

LÍFFÆRAÍGRÆÐSLUNEFND

# SKÝRSLA

LÍFFÆRAÍGRÆÐSLUNEFNDAR

**2010**

Fylgirit:  
Annual report 2010, Sahlgrenska I.C.

MAÍ 2010

# Skýrsla líffæraígræðslunefndar 2010

Líffæraígræðslunefnd var fyrst skipuð með bréfi, dags. 5. september 2007. Nú eru eftirtaldir skipaðir til setu í nefndinni:

Sveinn Magnússon skrifstofustjóri í velferðarráðuneyti, formaður  
Kristján Guðjónsson sviðsstjóri hjá Sjúkratryggingum Íslands  
Runólfur Pálsson yfirlæknir nýrnalækninga á Landspítala, fulltrúi Landspítala  
Elínborg Bárðardóttir læknir, fulltrúi landlæknis frá 1. september 2010  
Margrét B. Andrésdóttir læknir, fulltrúi Landspítala í stjórn Scandiatransplant

Í skipunarbréfi nefndarinnar segir að henni sé ætlað að vera ráðgefandi á sviði ígræðslu líffæra, safna saman upplýsingum um stöðu mála á hverjum tíma, svo sem fjölda líffæragjafa og líffæraþega, biðlista og biðtíma eftir líffæraígræðslu. Nefndin skal einnig gefa árlega út skýrslu um hið norræna samstarf, sem fer fram á vegum Scandiatransplant. Þá skal nefndin koma með tillögur til ráðherra um hugsanlegar breytingar á lögum eða reglugerðum sem varða málaflokkinn eftir því sem nefndin telur ráðlegast hverju sinni. Skipunartími nefndarinnar er frá 1. september 2007, til fjögurra ára.

Vísað er til skýrslna nefndarinnar fyrir árin 2003–2007 og 2008-2009.

Á árinu 2010 hélt nefndin 3 fundi.

## Líffæraígræðslur á Sahlgrenska-háskólasjúkrahúsinu í Gautaborg

Sahlgrenska-háskólasjúkrahúsið í Gautaborg tók við því mikilvæga hlutverki að veita Íslendingum þjónustu á sviði líffæraígræðslna 1. janúar 2010. Í gildandi samningi við Sahlgrenska-háskólasjúkrahúsið er sérstaklega kveðið á um að leitast verði við að tryggja íslenskum sjúklingum líffæri í samræmi við þann fjölda líffæra sem Íslendingar gefa.

Samstarfið hefur gengið vel það sem af er. Nýlega kom út ársskýrsla Sahlgrenska International Care og getur þar að líta yfirlit yfir líffæraígræðslur og aðra þjónustu sem stofnunin innti af hendi í þágu íslenskra sjúklinga á árinu 2010. Tölulegar upplýsingar um fjölda líffæragjafa og líffæraígræðslna er að finna aftar í þessari skýrslu.

## **Erlent samstarf**

### **1. CD-P-TO**

Formaður líffæraígræðslunefndar var 1. júlí 2007 skipaður fulltrúi Íslands í nefnd Evrópuráðsins um líffæraígræðslur (European Committee (Partial Agreement) on Organ Transplantation – CD-P-TO).

Formaður sótti fund í nefndinni, sem haldinn var í Dublin haustið 2007 en hefur ekki haft tæk á að sækja fundi síðan. Hins vegar hefur verið fylgst vel með upplýsingum og gögnum sem nefndinni berast. Einnig er miðlað þeim upplýsingum sem fyrirsurnir frá nefndinni hafa gefið tilefni til.

### **2. Scandiatransplant**

#### *Líffæragjafir og líffæraígræðslur innan vébanda Scandiatransplant 2010:*

Árið 2010 voru látnir líffæragjafir 388. Alls voru framkvæmdar 1686 líffæraígræðslur, þar af 1045 nýrnaígræðslur (369 nýru fengust úr lifandi gjöfum og 676 nýru úr látnum gjöfum), 323 lifraígræðslur (8 lifrar fengust úr lifandi gjöfum og 308 lifrar úr látnum gjöfum), 131 hjartaígræðsla, 1 hjarta- og lungnaígræðsla, 128 lungnaígræðslur (105 fengu tvö lungu, 23 eitt lungu), 43 brisígræðslur og 2 þarmaígræðslur. Þá voru gerðar 13 ígræðslur einangraðra briseyja. Fjörutíu sjúklingar fengu ígræðslu bæði nýra og briss, 8 fengu bæði lifur og nýra og 1 fékk hjarta og nýra. Þá fengu 4 sjúklingar ígræðslu tveggja nýrna samtímis. Loks fengu 7 sjúklingar nýra og briseyjar (beta-frumur).

Í lok árs 2010 voru alls 2117 sjúklingar skráðir á biðlistum eftir líffærum hjá Scandiatransplant, þar af biðu 1721 eftir nýra, 129 eftir lifur, 83 eftir hjarta, 136 eftir lunga eða lungum, 20 eftir brisi og nýra, 4 eftir brisi og 24 eftir briseyjum.

#### **Líffæragjafir**

Skoða þarf leiðir til að kynna líffæragjöf fyrir íslensku þjóðinni. Einkum er mikilvægt að gera fræðslu til almennings markvissari og beina henni í auknum mæli að ungu fólki. Ennfremur verður unnið að því að styrkja þjálfun heilbrigðisstarfsmanna sem annast öflun samþykkis frá aðstandendum til líffæragjafar. Skilgreina þarf hlutverk landlæknisembættisins í þessu mikilvæga verkefni. Tölulegar upplýsingar um líffæragjafir er að finna aftar í þessari skýrslu.

#### **Líffæraígræðslur á Landspítala**

Umfang ígræðslulækninga hefur aukist mikið á Landspítala á undanförunum árum. Halda þarf áfram uppbyggingu líffæraígræðsluteymis og ígræðslugöngudeildar spítalans svo unnt verði að veita sístækkandi hópi sjúklinga markvissa þjónustu í hæsta gæðaflokki.

Brynt er að tryggja að unnt verði að halda áfram ígræðslum nýrna frá lifandi gjöfum á Landspítala í framtíðinni. Mikið hefur mætt á skurðlæknunum Jóhanni Jónssyni, sem er í fullu starfi við Fairfax Hospital í Virginíu í Bandaríkjunum, og Eiríki Jónssyni, yfirlækni þvagfæraskurðlækninga á Landspítala. Ef viðhalda á þessu mikilvæga og vel heppnaða verkefni í framtíðinni þarf að hyggja að nýliðun meðal ígræðsluskurðlækna.

## Líffæragjafir og líffæraígræðslur – tölfræðilegar upplýsingar

**Tafla 1. Líffæri numin brott á Landspítala til ígræðslu**

	2006	2007	2008	2009	2010
Fjöldi líffæragjafa	5	0	2	6	3
<i>Líffæri numin á brott:</i>					
Bris	0	0	0	0	1
Hjarta	2	0	1	1	2
Lifur	4	0	2	4	3
Lunga	3	0	2	2	0
Nýra	10	0	4	12	6

Árið 2010 höfnuðu ættingjar líffæragjöf í einu tilviki. Í þremur tilvikum var ekki leitað til ættingja þar sem flug lá niðri vegna ösku í lofti. Í tveimur tilvikum var læknisfræðileg frábending líffæragjafar fyrir hendi.

**Tafla 2. Ígræðslur líffæra frá látnum gjöfum erlendis (fjöldi sjúklinga)**

	2006	2007	2008	2009	2010
Bris	0	0	0	0	0
Hjarta	0	0	0	2 <sup>#</sup>	3
Lifur	3	2	3 <sup>ψ</sup>	5	4
Lunga	1	1	0	0	2
Nýra	6	2	3	3 <sup>*</sup>	5

Árið 2010 fóru allar líffæraígræðslurnar fram á Sahlgrenska-háskólasjúkrahúsinu í Gautaborg. Fram til ársins 2010 voru líffæraígræðslur gerðar á Rigshospitalet í Kaupmannahöfn nema annað sé tekið fram.

<sup>#</sup>Ein hjartaígræðsla var framkvæmd á Sahlgrenska-háskólasjúkrahúsinu í Gautaborg.

<sup>\*</sup>Tvær lifrariígræðslur voru gerðar á Sahlgrenska-háskólasjúkrahúsinu í Gautaborg og ein á Rikshospitalet í Osló.

<sup>ψ</sup>Ein lifrariígræðsla var gerð á Rikshospitalet í Osló.

**Tafla 3. Ígræðslur líffæra frá lifandi gjöfum erlendis (fjöldi sjúklinga)**

	2006	2007	2008	2009	2010
Lifur	0	0	0	0	0
Nýra	1 <sup>*</sup>	1 <sup>*</sup>	0	0	1 <sup>*</sup>

<sup>\*</sup>Ígræðsla nýra frá lifandi gjafa á Rikshospitalet í Osló.

**Tafla 4. Ígræðslur nýrna frá lifandi gjöfum á Landspítala (fjöldi sjúklinga)**

	2006	2007	2008	2009	2010
Nýra	8	7	5	7	5

Frá því nýrnaígræðslur frá lifandi gjöfum hófust á Landspítala 2. desember 2003 og til ársloka 2010 voru framkvæmdar 46 ígræðslur.

**Tafla 5. Heildarfjöldi líffæraígræðslna 2006-2010**

Hjarta	5
Lifur	17 (allar frá látnum gjöfum)
Lungu	4
Nýra	54 (19 frá látnum gjöfum og 35 frá lifandi gjöfum)

**Tafla 6. Heildarfjöldi líffæraígræðslna frá því þær hófust árið 1970 til ársloka 2010**

Hjarta	12 ígræðslur í 11 sjúklinga
Hjarta og lungu	4 ígræðslur í 4 sjúklinga
Lungu	8 ígræðslur í 8 sjúklinga
Lifur	40 ígræðslur í 35 sjúklinga (3 börn fengu lifur frá lifandi gjöfum)
Nýra	208 ígræðslur í 183 sjúklinga (123 nýru komu frá lifandi gjöfum og 85 frá látnum gjöfum); 160 gengust undir ígræðslu nýra í eitt skipti, 21 sjúklingar gengust undir ígræðslu í tvö skipti og 2 í þrjú skipti

Bris hefur aldrei verið grætt í Íslending.

### Líffæraþegar

Í árslok 2010 voru 119 einstaklingar lifandi með starfandi ígrætt nýra. Á sama tíma var 71 sjúklingur í skilunarmeðferð. Því voru 62,6% sjúklinga með ígrætt nýra og telst það fremur hátt hlutfall. Það má að stærstum hluta þakka háu hlutfalli lifandi gjöfum en þeir voru 59,1% gjöfum á öllu tímabilinu og 64,8% síðustu 5 ár en það er með því hæsta sem þekkist. Níu einstaklingar voru á lífi með ígrætt hjarta og 2 með hjarta og lungu. Þá voru 6 einstaklingar á lífi með ígrædd lungu. Loks voru 29 einstaklingar með ígrædda lifur á lífi í árslok 2010.

## Kostnaður vegna líffæraígræðslna

Tafla 7. Kostnaður vegna líffæraígræðslna erlendis (millj. kr.) á verðlagi hvers árs

	2006	2007	2008	2009	2010
Sjúkrakostnaður	20,6	100,0	204,3	176,0	175,0
Ferðakostnaður	5,7	9,1	5,1	26,0	26,6
Dagpeningar	2,5	5,7	5,5	8,5	5,3
<b>Heildarkostnaður</b>	<b>28,8</b>	<b>114,8</b>	<b>214,9</b>	<b>210,5</b>	<b>206,9</b>

Tafla 8. Kostnaður vegna nýrnaígræðslna frá lifandi gjöfum á Landspítala (millj. kr.)

	2006	2007	2008	2009	2010
Kostnaður	46,7	34,5	41,5	58,8	49,7

Kostnaður Sjúkratrygginga Íslands (áður Tryggingastofnunar ríkisins) vegna nýrnaígræðslna samkvæmt samningi við Landspítala þar að lútandi.

### *Samanburður á kostnaði undanfarin ár:*

Heildarkostnaður Tryggingastofnunar ríkisins vegna líffæraígræðslna erlendis árin 2000 – 2004 var á verðlagi hvers árs eins og hér segir:

2000	kr. 47,7 milljónir
2001	kr. 33,9 milljónir
2002	kr. 110,2 milljónir
2003	kr. 107,4 milljónir
2004	kr. 33,5 milljónir
2005	kr. 56,5 milljónir

## Biðlistar eftir líffæraígræðslu

Tafla 9. Fjöldi sjúklinga á biðlista eftir líffærum í lok árs 2010

Hjarta	2*
Lungu	1
Lifur	3
Nýra	13*

\*Einn sjúklingur er á biðlista eftir bæði hjarta og nýra.

Reykjavík, júní 2011

Sveinn Magnússon

Kristján Guðjónsson

Margrét B. Andrésdóttir

Runólfur Pálsson

Elínborg Bárðardóttir

# Annual report 2010

## Organ donations and transplant operations for Icelandic citizens

Agreement between Sjúkratryggingar, Íslands  
and Sahlgrenska International Care AB in Gothenburg, Sweden

SAHLGRENKA I.C.

Advanced care at hand





## Annual report 2010

### Organ donations and transplant operations for Icelandic citizens

Agreement between Sjúkratryggingar Íslands  
and Sahlgrenska International Care AB (Sahlgrenska I.C.) in Gothenburg, Sweden.

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#### Introduction

The agreement between Sjúkratryggingar Íslands and Sahlgrenska I.C. regarding organ donations and transplant operations is valid from January 1<sup>st</sup>, 2010. The objective with the following report is primarily to summarize the year of activity and the results that were achieved, from a medical perspective as well as from a process perspective in connection with cooperation and routines. The second purpose is to constitute a foundation for a dialogue between the parties to continually keep developing and improving the cooperation for the benefit of the patients and the client Sjúkratryggingar Íslands.

#### Background

It has been allowed by Icelandic law to donate organs for transplant since 1991. Since no transplant surgeries (with deceased donors) have been done on Iceland, the Department of Health and the Icelandic National Insurance Administration have had formal agreements with various Nordic transplant centers for this. Between 1993 and 1996 the agreement partner was the Sahlgrenska University Hospital in Gothenburg. Between 1997 and 2009 Rigshospitalet in Copenhagen had this assignment. On December 1, 2003, the kidney transplant work with living donors started at the Landspítali University Hospital in Reykjavik. Landspítali University Hospital is the only hospital on Iceland that performs transplant surgeries and the hospital is also a formal representative in Scandiatransplant. In general, Iceland's expectations from the cooperation with Copenhagen were fulfilled thanks to a great number of living donors. With time the waiting time grew to three years for kidneys and the demand was expected to increase further. Furthermore, the waiting time for livers increased to more than two years. Resulting from the above the Sahlgrenska University Hospital once again got the opportunity to sign an agreement with Sjúkratryggingar Íslands over donation and transplant surgeries starting January 1, 2010. This report summarizes the work and cooperation of the initial year.

**Transplant Institute at Sahlgrenska University Hospital – leading in Sweden with all competence gathered in a new, well-adapted care facility.**

## **7,300 transplants since 1965**

Sahlgrenska University Hospital, one of Europe's largest university hospitals, has been leading the transplant area in Sweden since their first kidney transplant in 1965. With the foundation of the Transplant Institute in 2007 all organ transplants at the hospital were gathered together in the same organization.

The Sahlgrenska University Hospital is the only hospital in Scandinavia today with a complete transplant program for all organ transplants for children and adults. Today the hospital performs transplants of kidney, liver, heart, lung, pancreas and bowel.

Since 1965 approximately 7,300 patients have had new organs transplanted at the Sahlgrenska University Hospital.

Here is a short description of the different organ transplants performed at the Transplant Institute at Sahlgrenska University Hospital.

## **150 kidney transplants every year**

A kidney transplant is the best and most cost-effective treatment when the kidneys have stopped working. The most common diseases that cause the kidneys to stop working are a chronic kidney infection (glomerulonephritis) and diabetes. Transplants are not without risks and therefore not all patients with renal failure are offered transplants.

Patients that have been accepted for transplants from a deceased donor are put on a waiting list. There is a shortage of organs and the waiting time can be long, from a couple of months to years. The waiting time among other things depends on blood group and other medical factors. During the waiting time the patient has the option to be treated with hemodialysis. Every year approximately 150 kidney transplants are performed at the Transplant Institute and 40 of these are with living donors.

## **Liver transplant – a life saving procedure**

The Transplant Institute in Gothenburg has extensive experience of liver transplants with parts of a liver from a living donor. The most common thing is that a smaller piece from a grown donor liver is given to a child, but also transplants with bigger parts from the liver of a grown person to another grown person occur. 2010 five liver transplants with organs from living donors were performed with good results for both patients and donors.

The waiting time for liver transplants has increased gradually, partly because the amount of patients that have been accepted for transplants has increased, but also because the amount of deceased donors has decreased. The waiting time is normally between three to four months. The Transplant Institute has the ambition to continue leading the development of surgical methods that will result in a maximal use of available organs as well as to increase the amount of organs from living donors. 80 liver transplants are performed at the Transplant Institute every year.

## **Heart pumps save lives waiting for heart transplants**

The normal waiting time to receive a new heart is three to six months, but for the patients that have the heart pump HeartMate II for left-sided heart failure, the waiting time in the home is up to two years. For the newest type of heart pump, Excor-Berlin Heart, when both the left and right side of the heart is failing, the waiting time is six to twelve months. Adults can be treated at home during the waiting time while children spend the waiting time in the hospital.

The risk that patients die during the waiting time has decreased thanks to the supply of the latest mechanical heart pumps. Approximately 30 heart transplants in total, both for children and adults, are performed each year at the Transplant Institute.

## **Shortage of lungs for lung transplants**

During several years trials were made to only transplant one lung and in this way be able to transplant more patients. This ended in some results that were not so good and the change back to double-sided transplants was made. Today two thirds of all lung transplants are double-sided.

The Transplant Institute has succeeded in improving the apprehension of donated lungs. During the last year the Transplant Institute in cooperation with the Skåne University Hospital has developed new medicine technical equipment, the so called EVLP (ex vivo lung preservation) that allows for evaluation and optimization of marginal lung donors. Also the age limit for donors has been raised. These measures combined have resulted in that the hospital almost doubled the amount of lung transplants. In spite of more lung transplants being performed, the lack of organs results in that only a couple of patients with serious lung diseases can be offered a lung transplant.

In average one to two persons die every year while waiting for a lung transplant. In a limited amount of cases there is an option of surgically inserting a so called mechanical short-term heart pump. For this, the hospital has to send out an “urgent call” though in hopes to find a suitable organ for transplant.

Approximately 35 patients receive new lungs at the Transplant Institute every year.

## **Complicated to transplant pancreas**

Patients with insulin-treated diabetes can develop injuries to their kidneys and be in need of dialysis or a kidney transplant. Such patients can in some cases get both kidney and pancreas transplanted. Since the pancreas produces the insulin, the patients can in this way both be cured of their renal failure and their diabetes. This can also lead to the prevention of other diseases resulting from the patient’s diabetes and to a longer lifespan.

During the transplant the new pancreas is placed as an additional organ to the right of the abdomen. The patients’ own pancreas is left untouched. Today the pancreas is almost always transplanted together with a kidney that is placed in the left groin. Since a combined kidney- and pancreas transplant is a complicated surgery involving great risks for the patient, it can only be offered to a small amount of patients with diabetes and renal failure.

The last year about ten patients have undergone combined kidney and pancreas transplants at the Transplant Institute. The results are good with normal kidney function in all patients and one case of a lost pancreas graft.

## **Intestinal failure can lead to bowel transplant**

Patients whose bowels for different reasons cannot take on nourishment and fluids from the food they eat, suffer from intestinal failure. They need nourishment directly with drip into the blood. Unfortunately these patients risk getting life-threatening secondary diseases resulting from the nourishment drip and being in need of a bowel transplant.

Only the small intestines are transplanted since these are primarily responsible for taking in nourishment. Some patients with intestinal failure have diseases that affect other abdominal organs. These patients can be transplanted with a so called multi-organ transplant. They are in, addition to the small intestine, transplanted with a new stomach, duodenum, liver and pancreas. A total of five new organs are transplanted at the same time. The intestine is a very sensitive organ to transplant and only the intestine from relatively young deceased donors can be used for transplants. In Sweden there are not too many young deceased donors so the waiting time for a new intestine can become long, sometimes up to a couple of years. The result is that relatively many patients die waiting for a new intestine, particularly small children, unfortunately.

The results for multi-organ transplants are good with a patient survival rate of 80 percent after a year, which corresponds to the patient survival of liver transplants according to the European liver transplant register. Five year survival rate for the patient group is approximately 60 percent which in comparison is higher than after lung transplants.

The Transplant Institute at the Sahlgrenska University Hospital was the first unit in Scandinavia with an established program to care for patients with intestinal failure and to offer intestinal and multi-organ transplants. During the last ten years 20 patients have been transplanted with intestinal or multi-organ transplants.

## The unit for organ and tissue donation at Sahlgrenska University Hospital – an independent operation with well-defined processes and goals

The lack of organs to transplant is the biggest restricting factor for the work of the Transplant Institute. The possibility for the patients to survive is completely dependent on the will of their fellow humans to donate their organs after death. That is why it is essential that the health care does everything it can to make sure that people who want to donate their organs after death have the opportunity to do so.

The unit for organ and tissue donation at Sahlgrenska University Hospital has a responsibility to increase the amount of donors though optimizing the conditions for the involved parties. This is done through information and education to the hospitals that belong to the catchment area of the Sahlgrenska University Hospital. The unit for organ and tissue donation is also responsible for the coordination of organ donations and the transplants that follow.

### International development

Internationally the amount of organ donations decreased during 2008 (Eurotransplant's annual report 2009). In Sweden the amount in 2008 was higher than ever for both organ donations and transplants. The middle-age has been raised for all organs to meet the negative development in Europe. In Scandinavia the amount of donors per million inhabitants (p m i) has been among the highest in Sweden regarding heart and lung (6 p m i) and liver (13-15 p m i) but slightly lower than the average for kidneys (22-25 p m i). (Scandiorgan 2009-2010)

A poll that was published in 2008 and ordered by the Swedish Council for Organ and Tissue Donation showed that eight out of ten were willing to donate their organs and tissue after their death. But not more than half of the questioned had actively taken a stand in the question of organ and tissue donation. Almost 90 percent that had chosen a standpoint had done this **pro** donation. Only 40 percent of the questioned knew the opinion of their close ones.

In January 2011 the National Board of Health and Welfare in Sweden clarified the rules concerning life support measures and organ donation. According to this the intensive care can be continued if the development of a total cerebral infarction is suspected, however treatment cannot be initiated or started for the sole reason to make the donation of organs possible.

## During 2010 three donation operations were performed on Iceland

A multi-organ donation involves a lot of different personal categories with different specialties and functions. A multi-organ donation is resource-demanding, takes a long time to prepare and is a performance whose result relies on mutual efforts and commitment.

The situation demands an effective and coordinated organization, both at the Transplant Institute and at the donation hospital. During 2010 donation operations (multi-organ) were performed on three separate occasions on Iceland. The results were very satisfactory thanks to good communication and well functioning cooperation.

## Results 2010

### Amount of solid organs from Icelandic donors

Organ	2010
Heart	2
Lung	-
Liver	3
Kidney	6
Pancreas	1
Total	12

A total of ten patients were transplanted by using these organs.

Additional potential donors during 2010:

3 potential donors whose organs could not be transported due to the ash cloud.

2 potential donors with medical contraindication.

1 potential donor where the relatives did not give their consent.

### Amount of Icelandic patients transferred from the waiting list at Rigshospitalet in Copenhagen January 1, 2010

Organ	Total	On waiting list SU	Transplants done at SU
Heart	0		
Lung	1		1
Liver	1		1
Kidney	7	3 (+ 1*)	3
Pancreas	0		
Intestine	0		

\* 1 patient not active on the waiting list.

### Amount of Icelandic patients who received a mechanical heart pump at Sahlgrenska University Hospital

Mechanical heart pump	2009	2010
HeartMate II	1	1

## Amount of formal referrals from Icelandic doctors regarding transplants at Sahlgrenska University Hospital

Organ	Total	Under evaluation	On waiting list	Rejection	Transplant
Heart	7	2	2		3
Lung	6	1	1	2	2
Liver	9		2	4	3 (+ 1 PL)
Kidney	23	4	12 + 1*	1	5
Heart+kidney	1		1		

\* 1 patient not active on the waiting list.

## Average waiting time for Icelandic patients concerning organ transplants from a deceased donor (based on performed transplants during 2010)

Organ	Average waiting time
Heart	4.5 months
Lung	2.5 months
Liver	3.5 months
Kidney	3.5 months

## Amount of Icelandic patients who have undergone organ transplant with organs from a deceased donor

Organ	2003-2007 (Rigshospitalet Copenhagen)	2009 (Sahlgrenska) (outside agreement)	2010 (Sahlgrenska University Hospital)
Heart	2 (0.4/year)	1	3
Lung	4 (0.8/year)	-	2
Liver	10 (2/year)	2	4
Kidney	14 (2.8/year)	-	5
Pancreas	0	-	-
Intestine	0	-	-
Total	30 (6/year)	3	14

Source: Skýrsla 2008, page 5, Tafla 5.

## Amount of performed video conferences

Organ	Video conference
Heart	-
Lung	-
Liver	4
Kidney	3

## Experiences in 2010

### Evaluation before the transplant

During the last year there has been a certain suggestion of ambiguity regarding which patients that shall come to the Transplant Institute for evaluation. According to the agreement as many as possible of the evaluations should be done on Iceland and this has also been the case during 2010. Appendix I of the agreement under the heading Evaluation before transplant states that "It is desirable that patients come to the hospital for evaluation for 1-3 days before a major surgery" The decision regarding which patients should be investigated at the Transplant Institute shall always be preceded by a dialogue between responsible physicians at the Landspítali University Hospital and the Sahlgrenska University Hospital.

### Feedback routines

Sahlgrenska I.C. continuously informs Sjúkratryggingar Íslands as well as the transplant coordinator at Landspítali University Hospital when:

- a patient is to be called for transplant evaluation,
- a patient is put on the waiting list,
- a patient gets rejected,
- a transplant surgery has been performed, as well as when
- a patient is ready to be discharged or transferred to the hospital at home.

### Specialist consultation

During five visits on Iceland the following specialist consultations have been performed during 2010:

- Three specialist consultations have been performed for patients with both heart and kidney failure, respectively.
- A specialist consultation performed regarding follow-up of heart transplanted patients as well as patients on a heart transplant waiting list.
- A meeting regarding logistics for patients in need of a mechanical heart pump.

Further consultations were made when a cardiologist escorted an Icelandic transplant patient back to Iceland.

In addition, continuous consultations have been made over the phone, especially concerning patients who have undergone heart transplants. Sahlgrenska I.C. has judged that the beginning of the cooperation during 2010 has demanded a close dialogue for all involved parties and therefore no complementing billing has been done. For 2011 we see a need to formalize these consultations as a result of a major increase in heart and lung transplant candidates in comparison with the Copenhagen period. This is also a result of that these patients, according to the agreement, are not to be followed up in Sweden and that there at this point in time is no specially trained physician on Iceland for heart and lung transplant patients as there is for kidney and liver transplant patients. A more formalized cooperation needs to be started between the pathology units of the hospitals for the evaluation of hard to read biopsies, the exchange of knowledge as well as assuredness that there is support during Icelandic vacations.



According to the above, Sahlgremska I.C. will from now on continuously report on performed consultations and charge Sjúkratryggingar Íslands according to the agreement for specialist counselling that requires presence on Iceland. Continuous phone counselling is normally included. For patients where complications occur on Iceland and the phone counselling becomes so intense that it significantly effects the working day of the specialist in Gothenburg, this will be continuously reported and invoiced to Sjúkratryggingar Íslands.

## **Raised agreement prices**

The agreement prices as well as the compensation to donor hospitals will be raised in 2011 according to the agreement. The actual raise is decided by the Swedish Association of Local Authorities and Regions and will be announced to Sjúkratryggingar Íslands when it is communicated.

## **Icelandic priest in Gothenburg – valuable support for patients and relatives**

The Icelandic priest who is stationed in Gothenburg has during 2010 been a valuable support for the Icelandic patients and their relatives during their stay at the Transplant Institute.

During the year he has helped with transports, logistics and information for the Icelandic patients who have come for evaluation or transplants. He has to a great extent functioned as a language support in contacts between patients, relatives and hospital staff, especially when the patient neither spoke Swedish, Danish or English. For longer medical reviews by doctors or patient instruction before or after a surgery an interpreter has been hired. An important task and role for the Icelandic priest is to be a fellow human, supporting patients and relatives in their difficult situation. The visits to the patients at the hospital have been frequent which is particularly important for patients who arrive in Sweden without companion.

The cooperation between Sahlgremska I.C., Sahlgremska University Hospital and the Icelandic priest has been excellent and is an essential component of the wellbeing and safety of the patients.

## **Summary**

The cooperation with Iceland during 2010 has worked well in all essential parts, both from the view of Sahlgremska I.C. and Sahlgremska University Hospital. This applies to the organ donations and transplant operations as well as for the communication between the parties. The focus during 2010 has been to clarify the processes for the cooperation by a close dialogue between all parties.

A clear goal for both parties has been to work towards a higher donation frequency. The work was negatively affected by the ash cloud which resulted in that three potential organ donations could not be performed.

The ambition of the Sahlgremska University Hospital has been to minimize the care time for all patients as far as possible. Close contacts have been undertaken to ensure the correct time for the patient to return home. On average, the thoracic patients have been treated less than four weeks in the hospital whereof three patients have deviated with a longer care time and one recommitment. For kidney and liver patients the average time has been ten days with one deviation. The return home of some patients was delayed due to the ash cloud.

A significant deviation happened at the end of last year when a patient who was sent to Gothenburg urgently was not covered by the Icelandic insurance system. The event was investigated by Sjúkratryggingar in cooperation with Sahlgremska I.C. and reported to Landspítali.

# SAHLGRENSKA I.C.

Advanced care at hand

It is our hope that the life situation of all patients is stabilized and improved on a long-term and therefore the follow-up on Iceland is very important. It is also essential for the Transplant Institute to receive feedback on the results through annual reports since the Icelandic patients are a part of the Sahlgrenska University Hospital statistic of results and quality.

The Transplant Institute has established good contacts with each specialty on Iceland which has been rewarding for the whole operation in Gothenburg. It is our goal that our colleagues in Iceland feel welcome to contact us at anytime and also visit us for skill transfer and further education in the future.

We enter 2011 with the hopes of a continued good cooperation with all parties involved.