



Travel Grant Report Form

Name and origin of applicant

Kenneth Lindström Sweden

Purpose granted

The purpose of this trip was to constitute a foundation for a dialogue, to keep going and improve the good cooperation between us and Iceland, first and utmost to benefit the patients.

Amount granted

10 000 SEK

Time and place of visit

2011-10-10 – 2011-10-14 Reykjavik, Iceland

Report

Background

It has been allowed by Icelandic law to donate organs for transplantation 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 Sahlgrenska University Hospital in Gothenburg and between 1997 and 2009 Rigshospitalet in Copenhagen. In

January 2010 cooperation between Sahlgrenska University Hospital and Landspítali University Hospital restarted.

From 2003 living donor kidney transplantations were performed at Landspítali. This hospital is the only hospital on Iceland that performs transplant surgeries.

During 2010 five kidney transplantations were performed in two blood group A patients and in three with blood group O. Three patients had HLA antibodies.

Between 2011-01-01 until 2011-10-24 seven kidney patients has been transplanted. One of them had a combined pancreas and kidney transplantation and one a combined heart and kidney transplantation. Four patients were immunized and had HLA antibodies.

Swedish high risk patients, i.e. diabetics, patients with cardiovascular disease, elderly patients etc. are offered a pre transplant visit to the transplant centre in Gothenburg for evaluation and information about increased risks in connection with surgery and long term.

Due to economical reasons this offer is not presented to the Icelandic patients. (This fact was one of the reasons for my visit to Iceland).

The trip

The visit was from the 10th of October to the 14th. Just to make the trip in itself gave me an idea of what the patients experience when going home. Since there is no direct flights, I had to stop in Oslo on the way there and to stop in Copenhagen going back. Although I am healthy, I found the trip quite tiresome. This is something to should keep in mind when we send patients back home to Iceland. It was possible to check the luggage all the way. If you transit through Stockholm however, you have to claim your bag there and then check in it again.

On the Tuesday morning I met with Frank Pedersen and we payed a visit to the blood bank and tissue typing laboratory and saw Kristjana Bjarnadóttir, M. Sc, Manager of Landspítali tissue typing department. She showed us around. After that I proceeded to the out patient clinic, where I met with transplant coordinator Hildigunnur Fridjónsdóttir. Initially we discussed patient education and collaboration issues.

With a power point presentation I showed the data we have on the Icelandic patients. I was shown a patient brochure from Novartis and a manual made by dr Johann Jónsson, the doctor that perform the living donor transplantations in Iceland.

Next to see was our book "The life with a new kidney". After a tour round the hospital which ended up at the dialysis unit I met with staff nurse Margret Asgeisdóttir and her nurses.

Then I started meetings with the patients on the waiting list. The aim was to let them ask questions that seemed most important to them. I tried to see each patient at least 30 minutes. One of the

waiting list patients declined to talk to me. That patient initially asked for kidney and pancreas transplantation, but was only accepted for kidney transplantation. I told this patient I respected his wish not to talk to me. Was the reason that we had denied him the combined transplantation? He confirmed that but added that he believed he would never be transplanted. Another patient was hospitalized for a fungus peritonitis. In all I tried to give hope and encouragement. The most common question was of course “when will I be transplanted?” As far as possible I tried to give them a realistic estimate.

One of the patients was really angry and upset due to some misunderstanding in the past.

My aim there was to explain the Gothenburg waiting list criteria/rules. This patient claimed that his doctor had given him permission to skip the regular testing for HLA antibodies. He also wanted the hospital to pick him up with a helicopter if skiing in the mountains, when an offer for a kidney came. I carefully explained to him that without fresh blood samples we can't test the incoming kidneys against him. The helicopter discussion had to be between him and Landspítali. I stressed that in such circumstances, like skiing in the mountains one should use the system of being active or inactive on the waiting list. During the conversation his wife asked if she could become a donor in spite of the fact they did not have the same blood group? Then I explained that we perform ABO incompatible living donor kidney transplantations in Gothenburg. After a tensed meeting the patient said he was contented and left me smiling. Staff nurse M Asgeirsdóttir was present and a very good support.

On Wednesday I kept on seeing waiting list patients and a few patients under pretransplant evaluation. I also met with a social worker Anna Dora and had a rewarding discussion with her. She expressed a wish for a closer cooperation with the social workers at Sahlgrenska University Hospital. On return to Sweden, I addressed this wish to our social worker Lena Friedrich.

Hildigunnur Fridjonsdóttir also participated in this meeting. We talked about how Gothenburg deals with the issue of living anonymous donation. Contact has been initiated between Hildigunnur Fridjonsdóttir and transplant coordinator and MD Annette Lennerling, who is in charge of this very special kidney donations. A paper by Annette Lennerling on this issue has been sent to Iceland.

On Thursday I continued meeting the last patients. They were at the dialysis ward in the morning. I also paid a visit to ward 13 E. I was introduced to head nurse Hildur Tora Hallbjörnsdóttir,

Ward 13 E is the ward where the transplanted patients go for a few days after leaving Gothenburg. (Our kidney transplant patients normally go directly home and don't need to be hospitalized.) The collaboration between our ward 138-139 at the transplant centre and ward 13 E at Landspítali in general works satisfactory. However areas for improvement exist! Patients have arrived to Iceland with too little medicines for the next few days. Our routine is that the patients should be trained to read his medicine list and capable to load the medicine dispenser according to such a list.. Also several Icelandic patients have been sent back on a Friday. This means that the patients that need hospital care arrive to Landspítali very late on a Friday evening, when the staff is reduced for the

weekend. This gives suboptimal care and the Icelandic doctors and nurses would prefer that we send patients on Mondays up to Thursdays. The head nurse at the transplant centre is now informed about this.

On Thursday afternoon I had a meeting with doctor Runolfur Palsson, Head of the Renal Department and Hildigunnur Fridjonsdottir. We discussed collaboration and how to make it the very best.

Dr Palsson explained the current situation on Iceland. Limited resources and economical restrictions prevent the kidney section at Landspítali to recruit new nephrologists for training in the transplantation field. Another challenge is the increasing amount of patients with end stage kidney disease, which has been obvious the last three years. One reason for this is increased immigration.

On Iceland it's the nephrologists that inform the patients about how a transplantation is performed, what is required etc. High work load has an impact on how much patients will be informed and coached during the waiting period for transplantation. There is no tradition for nurses at the dialysis unit to give and repeat some of that information. From our horizon there is a problem with Icelandic patients never put inactive (ie not transplantable for the time being) on the waiting list and I met this patient with a fungus peritonitis, who was truly not transplantable. Here is an area for improvement

I explained the success we have had in different centres in Sweden by training and teaching especially interested nurses to take responsibility for information and education. Dr Palsson's vision was to create simple pathways by means of check lists.

We talked about the need of follow up reports after kidney transplantation. One way to report smoothly would be to train a secretary to do this on line. Contact has been made with our IT manager Torben Kling Pedersen about this possibility and he can not see any big problems with this

While on the waiting list we want reports on our patients every three months. Runolfur Palsson will see what he can do to improve this.

As a last matter I explained that transplant coordinators at Sahlgrenska can not connect Icelandic living donor kidney recipients to the Scandia Transplant database. In spite of this we have made one living donor kidney transplantation in May 2011. Dr Palsson will inform

the nephrologist responsible for Scandia Transplant issues about this.

All in all we had a great collaboration meeting. My Icelandic friends made a very interesting itinerary. I want to express my gratitude to all staff involved for taking the time to meet with me.

It seems to me that Iceland has a big challenge ahead of them ie. to handle the increase of patients with end stage kidney disease. We hope for an increase of deceased donor kidneys as well as an increased willingness for family members and other people close to the patient to donate kidneys.

Evaluation

Increased knowledge regarding possibilities and problems in the Icelandic health care system for end stage kidney disease patients.