Introduction

Dear Reader,

This Newsletter contains many contributions and reports on the events that have taken place in the past months. The annual meeting in Leiden, the EuroTransplant Information Exchange Platform (EUTIEP), in which best practices were identified and exchanged between the Eurotransplant member states. Also green light was given by the European Commission for the so-called European Framework for Evaluation of Transplanted OrganS (EFRETOS) project. In this project Eurotransplant leads a broad consortium that intends to achieve standardization of definitions and methods in the area of post transplant evaluation.

Many of the above activities took place in the light of developing national and international regulation. The focus of these activities is invariably related to quality and patient safety. History has shown that regulation can bring benefit in certain areas, but that it can also create havoc by destructively increasing costs and bureaucracy. Especially in the area of blood donation, -processing and distribution, regulation by the EU helped restore the public confidence in a system that had suffered greatly from scandals in the 80ties and 90ties.

To my opinion the current trend of increasing regulation by national and international authorities should be approached proactively in order to minimize the risk for unintended adverse effects:
1. It is important to be proactive: Better to develop and maintain best practices, than to have to adopt systems throughout Eurotransplant developed by others
2. It is essential that we either comply with our own rules or explain why we deviate.
3. In the event that one cannot comply for good reasons, stating this reason is essential. This is especially so when standards are being developed. That national and international authorities and politicians provide the correct arguments is also the responsibility of everyone within the community.

Recently, the current Minister of Health and Social Welfare of Croatia, Dr. Darko Milinović, informed Eurotransplant of the acquisition by the European Federation of Immunogenetics (EFI) of the Tissue typing lab in Rijeka. The fact that Rijeka complies with the EFI standard shows, that Eurotransplant and its member states takes its quality systems seriously.

This brings me to the third important aspect of this general trend of increasing regulation by national and international authorities. Over the years Eurotransplant has developed regulations for its own well being: allocation rules being the most prominent, but also general agreement on many aspects of organ procurement and organ characterization. These Eurotransplant regulations are a valuable asset: we take our responsibility seriously towards patients, towards each other, towards national authorities and to the 124,4 Million population of the Eurotransplant region.

Having our own regulations gives us a certain amount of freedom towards the outside world. However, every freedom always comes with its own responsibility: we must comply to our own rules or explain why we deviate. By doing this, we actually make evident to the outside world that we take our responsibility serious and that our systems, to assure quality and patient safety function adequately.

At the end of this editorial, I would like to thank the members of our community for their constructive contribution in the past year.

Merry Christmas and a happy 2009!

Arie Oosterlee
### Preliminary Monthly Statistics Eurotransplant January 01 – November 30

**Number of Post-Mortem Donors Used for Transplantation**

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**Number of Transplants Performed**

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He – Heart  Ki – Kidney  Pa – Pancreas  Li – Liver  SLu – Lung  BKi – both Kidneys  BLu – Both Lungs  SLi – Split Liver
Calendar of Events

26TH EUROTRANSPLANT WINTER MEETING
January, 22 – 24, 2009
Alpbach, Austria

For information: Ellen Houwaart
Eurotransplant
P.O. Box 2304
2301 CH Leiden, the Netherlands
Tel.: +31 71 5795795
Fax: +31 71 5790057
E-mail: wintermeeting@eurotransplant.nl
Website: www.eurotransplant.nl

30 YEARS OF PEDIATRIC LIVER TRANSPLANTATION IN EUROTRANSPLANT
February 13 – 14, 2008
Kiel, Germany

For information: Mrs. Sabine Schüder-Kruse
Tel.: +49 431 597 1691
Fax: +49 431 597 1304
E-mail: martin.burdelski@uksh-kiel.de
Conference Center: Hotel Maritim Kiel, www.maritim.de

38. Jahrestagung der Deutschen Gesellschaft für Thorax-, Herz- und Gefäßchirurgie
February 15 – 18, 2008
Stuttgart, Germany

For information: INTERPLAN
Albert-Rosshaupter-Straße 65
81369 München, Germany
Tel.: +49 89 5482 340
Fax: +49 89 5482 3443
Website: www.2009.dgthg-jahrestagung.de

16. WALTER-BRENDEL-KOLLEGE Für Transplantationsmedizin
March 6 – 11, 2008
Wildbad Kreuth, Germany

For information: Walter-Brendel-Kolleg
Organisationsbüro
Frau Schierenberg
Klinik d. Albert Ludwigs Universität
Abt. f. Viszeral- und Transplantationschirurgie
Hugstetterstr. 55
79106 Freiburg, Germany
Tel.: +49 761 270 2644
Fax: +49 761 270 2804
E-mail: maria.schierenberg@uniklinik-freiburg.de
Website: www.walter-brendel-kolleg.de

XI TTS BASIC SCIENCE SYMPOSIUM & I ESOT BASIC SCIENCE MEETING
March 12 – 15, 2008
Brussels, Belgium

For information: ESOT Office
Corso del Popolo, 8
35131 Padova, Italy
Tel.: +39 049 3005796
Fax: +39 049 2106306
E-mail: office@esot.org
Website: www.esot.org

IPTA 5th CONGRESS
April 18 – 21, 2009
Istanbul, Turkey

For information: Meredith O. Weiner
IPTA Meetings and Exhibits Manager
15000 Commerce Parkway, Suite C
Mt. Laurel, NJ 08054
Tel.: +1 856 642 4419
Fax: +1 856 439 0525
E-mail: mweiner@ahint.com
Website: www.iptaonline.org

ISHLT 29th Annual Meeting and Scientific Sessions
April 22 – 25, 2009
Paris, France

For information: Lisa Edwards
14673 Midway Road, Suite 200
Addison, Texas 75001, USA
Tel.: +1 972 490 9495
Fax: +1 972 490 9499
E-mail: lisa.edwards@ishlt.org
Website: www.ishlt.org

2009 AMERICAN TRANSPLANT CONGRESS
May 30 – June 3, 2009
Boston, MA, USA

For information visit www.atcmeeting.org/2009

14th Congress of the ESOT
August 30 – September 2, 2009
Paris, France

For information: Congress Secretariat
ESOT Office
Corso del Popolo, 8
35131 Padova, Italy
Tel.: +39 049 3005796
Fax: +39 049 2106306
E-mail: esot2009@esot.org
Website: www.esot.org/congresses

2009 Organ Donation Congress - 10th ISDOP & 16th ETCO
October 4 – 7, 2009
Berlin, Germany

For information: Conference Office Agentur
WOK GmbH
Paisadenstr. 48
10243 Berlin, Germany
Tel.: +49 30 49 85 50-31/-32
Fax: +49 30 49 85 50 30
E-mail: info@isodp2009.org
Website: www.isodp2009.org
During its meeting of October 10, 2008 the Eurotransplant International Board decided to endorse the Declaration of Istanbul on organ trafficking and transplant tourism:

The Declaration of Istanbul on Organ Trafficking and Transplant Tourism

Participants in the international Summit on Transplant Tourism and Organ Trafficking convened by The Transplantation Society and International Society of Nephrology in Istanbul, Turkey, April 30–May 2, 2008

Preamble

Organ transplantation, one of the medical miracles of the twentieth century, has prolonged and improved the lives of hundreds of thousands of patients worldwide. The many great scientific and clinical advances of dedicated health professionals, as well as countless acts of generosity by organ donors and their families, have made transplantation not only a life-saving therapy but a shining symbol of human solidarity. Yet these accomplishments have been tarnished by numerous reports of trafficking in human beings who are used as sources of organs and of patient-tourists from rich countries who travel abroad to purchase organs from poor people. In 2004, the World Health Organization, called on member states “to take measures to protect the poorest and vulnerable groups from transplant tourism and the sale of tissues and organs, including attention to the wider problem of international trafficking in human tissues and organs” (1).

To address the urgent and growing problems of organ sales, transplant tourism and trafficking in organ donors in the context of the global shortage of organs, a Summit Meeting of more than 150 representatives of scientific and medical bodies from around the world, government officials, social scientists, and ethicists, was held in Istanbul from April 30 to May 2, 2008. Preparatory work for the meeting was undertaken by a Steering Committee convened by The Transplantation Society (TTS) and the International Society of Nephrology (ISN) in Dubai in December 2007. That committee’s draft declaration was widely circulated and then revised in light of the comments received. At the Summit, the revised draft was reviewed by working groups and finalized in plenary deliberations.

This Declaration represents the consensus of the Summit participants. All countries need a legal and professional framework to govern organ donation and transplantation activities, as well as a transparent regulatory oversight system that ensures donor and recipient safety and the enforcement of standards and prohibitions on unethical practices.

Unethical practices are, in part, an undesirable consequence of the global shortage of organs for transplantation. Thus, each country should strive both to ensure that programs to prevent organ failure are implemented and to provide organs to meet the transplant needs of its residents from donors within its own population or through regional cooperation. The therapeutic potential of deceased organ donation should be maximized not only for kidneys but also for other organs, appropriate to the transplantation needs of each country. Efforts to initiate or enhance deceased donor transplantation are essential to minimize the burden on living donors. Educational programs are useful in addressing the barriers, misconceptions and mistrust that currently impede the development of sufficient deceased donor transplantation; successful transplant programs also depend on the existence of the relevant health system infrastructure.
Access to healthcare is a human right but often not a reality. The provision of care for living donors before, during and after surgery—described in the report of the international forums organized by TTS in Amsterdam and Vancouver (2-4)—is no less essential than taking care of the transplant recipient. A positive outcome for a recipient can never justify harm to a live donor; on the contrary, for a transplant with a live donor to be regarded as a success means that both the recipient and the donor have done well.

This Declaration builds on the principles of the Universal Declaration of Human Rights (5). The broad representation at the Istanbul Summit reflects the importance of international collaboration and global consensus to improve donation and transplantation practices. The Declaration will be submitted to relevant professional organizations and to the health authorities of all countries for consideration. The legacy of transplantation must not be the impoverished victims of organ trafficking and transplant tourism but rather a celebration of the gift of health by one individual to another.

Definitions

Organ trafficking is the recruitment, transport, transfer, harboring or receipt of living or deceased persons or their organs by means of the threat or use of force or other forms of coercion, of abduction, of fraud, of deception, of the abuse of power or of a position of vulnerability, or of the giving of, or the receiving by, a third party of payments or benefits to achieve the transfer of control over the potential donor, for the purpose of exploitation by the removal of organs for transplantation (5).

Transplant commercialism is a policy or practice in which an organ is treated as a commodity, including by being bought or sold or used for material gain.

Travel for transplantation is the movement of organs, donors, recipients or transplant professionals across jurisdictional borders for transplantation purposes. Travel for transplantation becomes transplant tourism if it involves organ trafficking and/or transplant commercialism or 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.

Principles

1. National governments, working in collaboration with international and non-governmental organizations, should develop and implement comprehensive programs for the screening, prevention and treatment of organ failure, which include:
   a. The advancement of clinical and basic science research;
   b. Effective programs, based on international guidelines, to treat and maintain patients with end-stage diseases, such as dialysis programs for renal patients, to minimize mortality and morbidity, alongside transplant programs for such diseases;
   c. Organ transplantation as the preferred treatment for organ failure for medically suitable recipients.
2. Legislation should be developed and implemented by each country or jurisdiction to govern the recovery of organs from deceased and living donors and the practice of transplantation, consistent with international standards.
   a. Policies and procedures should be developed and implemented to maximize the number of organs available for transplantation, consistent with these principles;
   b. The practice of donation and transplantation requires oversight and accountability by health authorities in each country to ensure transparency and safety;
   c. Oversight requires a national or regional registry to record deceased and living donor transplants;
   d. Key components of effective programs include public education and awareness, health professional education and training, and defined responsibilities and accountabilities for all stakeholders in the national organ donation and transplant system.

3. Organs for transplantation should be equitably allocated within countries or jurisdictions to suitable recipients without regard to gender, ethnicity, religion, or social or financial status.
   a. Financial considerations or material gain of any party must not influence the application of relevant allocation rules.

4. The primary objective of transplant policies and programs should be optimal short- and long-term medical care to promote the health of both donors and recipients.
   a. Financial considerations or material gain of any party must not override primary consideration for the health and well-being of donors and recipients.

5. Jurisdictions, countries and regions should strive to achieve self-sufficiency in organ donation by providing a sufficient number of organs for residents in need from within the country or through regional cooperation.
   a. Collaboration between countries is not inconsistent with national self-sufficiency as long as the collaboration protects the vulnerable, promotes equality between donor and recipient populations, and does not violate these principles;
   b. Treatment of patients from outside the country or jurisdiction is only acceptable if it does not undermine a country’s ability to provide transplant services for its own population.

6. Organ trafficking and transplant tourism violate the principles of equity, justice and respect for human dignity and should be prohibited. Because transplant commercialism targets impoverished and otherwise vulnerable donors, it leads inexorably to inequity and injustice and should be prohibited. In Resolution 44.25, the World Health Assembly called on countries to prevent the purchase and sale of human organs for transplantation.
   a. Prohibitions on these practices should include a ban on all types of advertising (including electronic and print media), soliciting, or brokering for the purpose of transplant commercialism, organ trafficking, or transplant tourism.
   b. Such prohibitions should also include penalties for acts—such as medically screening donors or organs, or transplanting organs—that aid, encourage, or use the products of, organ trafficking or transplant tourism.
   c. Practices that include vulnerable individuals or groups (such as illiterate and impoverished persons, undocumented immigrants, prisoners, and political or economic refugees) to become living donors are incompatible with the aim of combating organ trafficking, transplant tourism and transplant commercialism.
Proposals

Consistent with these principles, participants in the Istanbul Summit suggest the following strategies to increase the donor pool and to prevent organ trafficking, transplant commercialism and transplant tourism and to encourage legitimate, life-saving transplantation programs:

To respond to the need to increase deceased donation:

1. Governments, in collaboration with health care institutions, professionals, and non-governmental organizations should take appropriate actions to increase deceased organ donation. Measures should be taken to remove obstacles and disincentives to deceased organ donation.
2. In countries without established deceased organ donation or transplantation, national legislation should be enacted that would initiate deceased organ donation and create transplantation infrastructure, so as to fulfill each country’s deceased donor potential.
3. In all countries in which deceased organ donation has been initiated, the therapeutic potential of deceased organ donation and transplantation should be maximized.
4. Countries with well-established deceased donor transplant programs are encouraged to share information, expertise and technology with countries seeking to improve their organ donation efforts.

To ensure the protection and safety of living donors and appropriate recognition for their heroic act while combating transplant tourism, organ trafficking and transplant commercialism:

1. The act of donation should be regarded as heroic and honored as such by representatives of the government and civil society organizations.
2. The determination of the medical and psychosocial suitability of the living donor should be guided by the recommendations of the Amsterdam and Vancouver Forums (2-4).
   a. Mechanisms for informed consent should incorporate provisions for evaluating the donor’s understanding, including assessment of the psychological impact of the process;
   b. All donors should undergo psychosocial evaluation by mental health professionals during screening.
3. The care of organ donors, including those who have been victims of organ trafficking, transplant commercialism, and transplant tourism, is a critical responsibility of all jurisdictions that sanctioned organ transplants utilizing such practices.
4. Systems and structures should ensure standardization, transparency and accountability of support for donation.
   a. Mechanisms for transparency of process and follow-up should be established;
   b. Informed consent should be obtained both for donation and for follow-up processes.
5. Provision of care includes medical and psychosocial care at the time of donation and for any short- and long-term consequences related to organ donation.
   a. In jurisdictions and countries that lack universal health insurance, the provision of disability, life, and health insurance related to the donation event is a necessary requirement in providing care for the donor;
   b. In those jurisdictions that have universal health insurance, governmental services should ensure donors have access to appropriate medical care related to the donation event;
   c. Health and/or life insurance coverage and employment opportunities of persons who donate organs should not be compromised;
   d. All donors should be offered psychosocial services as a standard component of follow-up;
   e. In the event of organ failure in the donor, the donor should receive:
      i. Supportive medical care, including dialysis for those with renal failure, and
      ii. Priority for access to transplantation, integrated into existing allocation rules as they apply to either living or deceased organ transplantation.

6. Comprehensive reimbursement of the actual, documented costs of donating an organ does not constitute a payment for an organ, but is rather part of the legitimate costs of treating the recipient.
   a. Such cost-reimbursement would usually be made by the party responsible for the costs of treating the transplant recipient (such as a government health department or a health insurer);
   b. Relevant costs and expenses should be calculated and administered using transparent methodology, consistent with national norms;
   c. Reimbursement of approved costs should be made directly to the party supplying the service (such as to the hospital that provided the donor’s medical care);
   d. Reimbursement of the donor’s lost income and out-of-pocket expenses should be administered by the agency handling the transplant rather than paid directly from the recipient to the donor.

7. Legitimate expenses that may be reimbursed when documented include:
   a. the cost of any medical and psychological evaluations of potential living donors who are excluded from donation (e.g., because of medical or immunologic issues discovered during the evaluation process);
   b. costs incurred in arranging and effecting the pre-, peri- and post-operative phases of the donation process (e.g., long-distance telephone calls, travel, accommodation and subsistence expenses);
   c. medical expenses incurred for post-discharge care of the donor;
   d. lost income in relation to donation (consistent with national norms).
References


* The Participants in the International Summit on Transplant Tourism and Organ Trafficking and the manner in which they were chosen and the meeting was organized were as follows:

Process and Participant Selection

Steering Committee:

The Steering Committee was selected by an Organizing Committee consisting of Mona Alulkami, Jeremy Chapman, Francis Delmonico, Mohammad Sayegh, Faisal Shaheen, and Amka Tibeit.

The Steering Committee was composed of leadership from The Transplantation Society, Including its President-elect and the Chair of its Ethics Committee, and the International Society of Nephrology, including its Vice President and individuals holding Council positions. The Steering Committee had representation from each of the continental regions of the globe with transplantation programs.

The mission of the Steering Committee was to draft a Declaration for consideration by a diverse group of participants at the Istanbul Summit. The Steering Committee also had the responsibility to develop the list of participants to be invited to the Summit meeting.

Istanbul Participant Selection:

Participants at the Istanbul Summit were selected by the Steering Committee according to the following considerations:

- The country liaisons of The Transplantation Society representing virtually all countries with transplantation programs;
Representatives from international societies and the Vatican;
- Individuals holding leadership positions in nephrology and transplantation;
- Stakeholders in the public policy aspect of organ transplantation; and
- Ethicists, anthropologists, sociologists, and legal scholars well-recognized for their writings regarding transplantation policy and practice.

No person or group was polled with respect to their opinion, practice, or philosophy prior to the Steering Committee selection or the Istanbul Summit.

After the proposed group of participants was prepared and reviewed by the Steering Committee, they were sent an letter of invitation to the Istanbul Summit, which included the following components:
- The mission of the Steering Committee to draft a Declaration for all Istanbul participants' consideration;
- The agenda and work group format of the Summit;
- The procedure for the selection of participants;
- The work group topics;
- An invitation to the participants to indicate their work group preferences;
- The intent to communicate a draft and other materials before the Summit convened;
- The Summit goals to assemble a final Declaration that could achieve consensus and would address the issues of organ trafficking, transplant tourism and commercialism, and provide principles of practice and recommended alternatives to address the shortage of organs;
- An acknowledgment of the funding provided by Astellas Pharmaceuticals for the Summit;
- Provision of hotel accommodations and travel for all invited participants.

Of approximately 170 persons invited, 160 agreed to participate and 152 were able to attend the Summit in Istanbul on April 30-May 2, 2008. Because work on the Declaration at the Summit was to be carried out by dividing the draft document into separate parts, Summit invitees were assigned to a work group topic based on their response concerning the particular topics on which they wished to focus their attention before and during the Summit.

Preparation of the Declaration:

The draft Declaration prepared by the Steering Committee was furnished to all participants with ample time for appraisal and response prior to the Summit. The comments and suggestions received in advance were reviewed by the Steering Committee and given to leaders of the appropriate work group at the Summit. (Work group leaders were selected and assigned from the Steering Committee.)

The Summit meeting was formatted so that breakout sessions of the work groups could consider the written responses received from participants prior to the Summit as well as comments from each of the work group participants. The work groups elaborated these ideas as proposed additions to and revisions of the draft. When the Summit reconvened in plenary session, the Chairs of each work group presented the outcome of their breakout session to all Summit participants for discussion. During this process of review, the wording of each section of the Declaration was displayed on a screen before the plenary participants and was modified in light of their comments until consensus was reached on each point.

The content of the Declaration is derived from the consensus that was reached by the participants at the Summit in the plenary sessions which took place on May 1 and 2, 2008. A formatting group was assembled immediately after the Summit to address punctuation, grammatical and related concerns and to record the Declaration in its finished form.
Eurotransplant endorses the Declaration of Istanbul on organ trafficking and transplant tourism

Participants in the Istanbul Summit

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Eurotransplant endorses the Declaration of Istanbul on organ trafficking and transplant tourism.
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* = Members of the Steering Committee. (William Couser, USA, was also a member of the Steering Committee but was unable to attend the Summit.)
Speech by Mr. Christiaan Decoster, director-general of Federal Service of Health, Food Chain Safety and Environment, to Prof. Yves Vanrenterghem

Prof. Yves Vanrenterghem is - already for many years - a member of the scientific community for which the Eurotransplant International Foundation stands. He even was the president of Eurotransplant for almost ten years. During this period he appeared to be a wise and competent leader who among other things introduced democracy and the principle of national representation in Eurotransplant. He was at the helm of the foundation at time that new countries, such as Slovenia and Croatia, approached Eurotransplant in order to become a member of Eurotransplant. Prof. Vanrenterghem was closely involved in the joining of both countries in Eurotransplant. Under his guidance Eurotransplant developed into a mature, professional organization which currently serves a population of 124 million European inhabitants. He acted as a real European with his natural skills to bring and to keep people together, a real builder of bridges so to say. His great efforts, loyalty and dedication shown over all these years have been extraordinary inspiring and supportive for the Eurotransplant Board and Directors. An organization that started as a research project and in the meantime has grown to an organization which is considered to be reliable enough as to be contracted by national authorities and ministries, can only realize such a development with a stable competent leader who Prof. Vanrenterghem always has been.

In this respect, transplant patients in the Eurotransplant countries, certainly also Belgian patients, owe him many thanks.

Besides his responsibility as a Eurotransplant Board member, he has an outstanding reputation in the medical world, being one of the world famous experts in the field of renal transplantation. This reputation will certainly have contributed to the fact that he holds a prominent position within The Transplantation Society as well as the vice-chairmanship of the so-called Global Alliance for Transplantation.

In 2007, festivities and a symposium took place on occasion of the 3,000th renal transplantation in the hospital of the Catholic University Leuven which was carried out under guidance of the leader of the department, Prof. Yves Vanrenterghem. As a tribute to him many prominent researchers from all over the world gave presentations and attended the symposium. This tribute shows that Prof. Vanrenterghem’s high quality is appreciated among colleagues for which reason he is a well distinguished person in the transplantation field.

All these qualifications have resulted in the fact that his Royal Highness, King Albert II has been graciously pleased to award, as a token of appreciation for all services rendered, upon Royal Resolution dated July 2, 2008, the civil decoration of RIDDER in de LEOPOLDSORDE (Knight of The Order of Leopold) to

PROFESSOR YVES FRANS CHARLES VANRENTERGHEM
Dear colleagues and friends,

This year, we do not have a jubilee to celebrate, no royal visit, no fancy hotel; we are back to business as usual. Nevertheless, this last year was another exciting year for the foundation and I think we successfully continued to set the course for the future.

A part of this preparation for the future was an assessment of the Eurotransplant organization as well as of its financial and organizational risks.

The background is that Eurotransplant operates currently in a network of many stakeholders, with highly educated personnel, allocating more than 6,000 organs each year. The organization developed and grew alongside the growing amount of allocated organs and the increasing demand for information (the so-called requests) and other tasks.

A lot of these additional tasks were explicitly accounted for in the yearly budget, but there was also a steadily growing number of customer demands fulfilled by Eurotransplant, assuming that these activities were an implicit part of its mandate. Just remember on how many occasions the expertise of the directors has been sought during the last year – over and above their routine duties in the office.

There were strong indications that Eurotransplant is structurally under-funded in relation to its current level of activities and responsibilities. In order to develop a comprehensive vision on what Eurotransplant and its contracting parties want to achieve in the future, how the foundation should be organized to enable this and what funding is necessary for this, a consultancy company, Lokerse, was selected and contracted. The assignment for this project was designed in close cooperation between the Eurotransplant management and the representatives of the Health Care Insurance Companies, who also agreed to cover the costs of this evaluation.

The project is divided in four milestones:
- determination of the current situation;
- risk analysis;
- future budget proposal;
- long term strategy.

Just to mention a few points of the evaluation so far: Lokerse came up with the suggestion to develop and professionalize a comprehensive array of services on top of what is strictly mandated in the contracts and negotiate these services with the different national authorities. They came to the conclusion that certain departments need to be reinforced or that the website has to be modernized; it has to become more user-friendly.

...and Eurotransplant should create an independent data management department that only focuses on the task of collecting, cleaning, analyzing, reporting as well as exchanging data with other organizations.

I can only support this proposal since I am convinced that the collection, analysis and exchange of data will be in addition to our core business, the allocation, a major and utmost important issue for the future role of Eurotransplant within the European setting.

Talking about the European setting, I have the pleasure to welcome Dr. Tapani Piha, the Head of Health Law and International Unit of the Directorate-General for Health and Consumers of the European Commission, who will talk about the European Commissions’ initiative regarding organ donation and transplantation.

Therefore, I will not go into the details. Since this regulatory initiative – which might even become a directive – could have a major impact on the functioning of our organization, I will just briefly mention the most important aspects.

The initiative lays down standards of quality and safety for human organs intended for transplantation. It applies to the donation, procurement, testing, preservation, transport, transplantation and characterization of human organs intended for transplantation.

The only point in this initiative which deals with the exchange of human organs is related to third countries:

Member States shall ensure that all exchanges of human organs from or to third countries are submitted to authorization by the competent authority or authorities. For the purpose of this paragraph, countries which are members of a European organ exchange organization shall not be considered as third countries. I appreciate this inclusion very much.

Let’s stay a moment with the Health and Consumer Protection Directorate. I had the pleasure to become acquainted with the new European Commissioner for Health and Consumer Protection, Mrs. Androulla VASSILIOU during a symposium on organ donation in the Bavarian embassy in Brussels. I used the opportunity to invite her and on September 6, she visited the Eurotransplant office. It was a bit difficult to organize a lively office on a Saturday, but we managed and the directors and I could explain her and her staff the workings of Eurotransplant for more than 2 hours.

She gave special attention and support to the Eurotransplant’s ongoing efforts to try and cooperate more closely
with Eastern European Countries – to mention particularly Hungary, Poland and the Czech Republic - where we started or continued respective initiatives.

Eurotransplant’s recent initiative, to host an information exchange platform on organ donation for the ministries of Health Care of the member states – I will explain the background in a moment - was received with interest as this type of communication was also planned to be organized by the European Commission. It was agreed that Eurotransplant would send an invitation for the next meeting to the cabinet of the Commissioner.

And last not least the commissioner expressed to expect much from the results of the European Project on setting standards for post transplant evaluation:

Now - what is that? Eurotransplant is project leader of a broad coalition of organ exchange organizations and the European Society for Organ Transplantation. The group includes

- Agence de la Biomédecine (France)
- UK Transplant
- Organización Nacional de Trasplantes (Spain)
- Instituto Superiore di Sanità (Italy)
- Scandiatransplant
- With subcontracts to NTS and the DSO

The project is called EFRETOS which stands for European Framework for Evaluation of Transplanted OrganS

The general objective of this project, which is funded by the European Commission, is to develop a common data dictionary, define a methodology and delineate legal & technical requirements for registry management. This is a prerequisite for creating a pan-European registry of registries for post-transplant outcome data.

This project will allow a comprehensive view on the quality and safety in transplantation in Europe in general and evaluate best practices to promote the health and safety standards in all member states.

Ultimately, the set up of a registry of registries will lead to a more efficient and safer organ allocation system. And being the project leader, our goal should be to host this future registry of registries.

So we have on one side the initiative of expanding the Eurotransplant community by offering help and support to eastern European countries, we have the cooperation with the organ procurement and exchange organizations from the old Europe, South, West North, with Eurotransplant being the leader within the framework of the EFRETOS project, but our major partners are still the national authorities in the member countries of Eurotransplant.

Lets go back a year. We had the Ministers Conference on the occasion of our 40th anniversary near Maastricht, the Netherlands. There, it was decided to create an information exchange platform so that the ET countries can benefit from each other’s experiences and best practices. And the first meeting of the Eurotransplant information exchange platform took place on Wednesday, June 18, 2008 at the Eurotransplant office.

I chaired this meeting with high representatives of the respective ministries of each of our countries, the Board members representing their country in the Eurotransplant Board - and the Eurotransplant Directors.

We discussed legal aspects as well as strategies for optimization of organ donation by demonstrating successful approaches – Dirk Ysebaert reported about the Belgian experience, Rudi Steininger about the Austrian - as well as less successful ones. Then the representatives of the ministries had an opportunity to give their opinion about the pros and cons of their national system.

In summary, all were much in favor of continuing and extending this platform and to include not only organ donation as a subject but also the set up of a post transplant registry into the next rounds of discussion. It was suggested to also invite the heads of the organ procurement organizations for the next meeting, which will be on October 24, and as I have mentioned before, the European Commissioner intends to send a representative as well.

Last not least I would like to mention a quite exhausting and demanding summit meeting, which was attended by the 2 directors, Yves Vanrenterghem and me as a part of more than 150 representatives of scientific and medical bodies from around the world, government officials, social scientists, and ethicists. It was held in Istanbul from April 30 to May 2 and ended with a consensus, the Declaration of Istanbul on organ trafficking and transplant tourism. One of the key sentences of this declaration reads:

*Organ trafficking and transplant tourism violate the principles of equity, justice and respect for human dignity and should be prohibited.*

Our Past President will certainly give you more information about this utmost important declaration during the Presidential symposium and I hope that based on his information, the Board will accept this declaration – as many other organizations have already done - as an important part of the Eurotransplant policy.

Before I finish, I would like to stay a moment with our Past President. Yves Vanrenterghem has been a Board member of the Eurotransplant Foundation for 15 years now, he was President of our organization for 9 years and past president for the last three years. Based on his outstanding dedication to our organization, the Board felt the obligation to express its appreciation for the work he did in the Eurotransplant interest. Therefore, the Board unanimously decided to appoint Prof. Vanrenterghem as 'Honorary President'.
We would like him to continue to be a Eurotransplant ambassador, for example in his function in the Council of the Transplantation Society or as vice-chairman of the Global Alliance for Transplantation.

Prof. Pichlmayr once gave Jon van Rood a statue, which became a symbol for the Presidency. It was passed onto Yves and stayed in his office for 9 years before he handed it over to me.

I found a craftsman in Bavaria who made a copy of this statue – and I would like to hand it over to you – Yves – as a symbol of you being our Honorary President.

I sincerely hope you have a good time here in Leiden and you use the opportunity to exchange opinions, experiences, best practices or just some new stories and rumors with your colleagues and friends from the Eurotransplant community.

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Eurotransplant Winter Meeting 2009

Program overview

**Thursday, January 22, 2009**
Venue: Hotel Alpbacherhof

- 14:00 – 18:00 hrs  Meeting of the Board of Eurotransplant
- 20:00 hrs  Welcome and dinner

**Friday, January 23, 2009**
Venue: Congress Center Alpbach

- 15:30 – 17:30 hrs  Lectures by Key Opinion Leaders
- 17:30 – 18:00 hrs  coffee break
- 18:00 – 19:45 hrs  New developments
- 20:00 hrs  Dinner

**Saturday, January 24, 2009**
Venue: Congress Center Alpbach

- 15:30 – 17:30 hrs  Workshops
- 17:30 – 18:00 hrs  coffee break
- 18:00 – 19:30 hrs  Workshop reports & Keynote speakers

Venue: to be announced
- 20:00 – 00:00 hrs  Dinner & Party

For registration we invite you to visit our website: www.eurotransplant.nl
Part one

The objective of this report is to be accountable towards the internal and external stakeholders of the Foundation in Austria, Belgium, Croatia, Germany, Luxembourg, the Netherlands and Slovenia.

In this report, I account for the activities and initiatives that were undertaken within Eurotransplant since the last director’s report that I presented to you in 2007 in Noordwijk. Since my last directors report many things happened. Obviously, the good work was done by

- doctors and nurses of the donor hospitals,
- the transplant centers,
- the tissue typer’s,
- the transplant coordinators and by
- many others like the people working at the Leiden office.

First of all, to our deep regret one of the co-workers of Eurotransplant died this year on March 11: Wouter Hovekamp. He was a highly competent and an intelligent IT developer who was also an idealist which was why he wanted to work for Eurotransplant. His memory inspires us: he was a PhD biologist who kept up his interest during his whole career in many divers aspects of nature. Not only did he discover several new species of mammals in Corsica, he also led an expedition to Spitsbergen in which a team rowed around this island armed with a gun to fend off the hungry polar bears.

Core processes and financial results

To produce our services, Eurotransplant manages its three core processes:

- Allocation,
  ET’s duty desk was involved in the allocation of 6385 organs, which is an increase of 7.3 % compared to 2006.
- Algorithm development,
  In 2007 a total of 431 improvements, bugs and new features where realized in the different Eurotransplant applications.
- Registry
  > 550 requests for information from National Authorities, TC, Pt’s, Press, etc. Transplant centers, patients, press etc.

Financial results

Several unforeseen developments during the financial year 2007 made the organization use some of its reserves. Eurotransplant has the intention to build up its reserves again to a level to be determined by an objective assessment in 2008. Apart from incidental costs like i.e. the unforeseen opportunity to host the ministers of the Eurotransplant Countries and incidental organizational restructuring, several cost categories lead to the conclusion that together with Eurotransplant’s financing authorities more insight will have to be realized in the cost structure and requested service levels.

Towards the end of the year an increase in tariff for the year 2008 has been agreed upon with the health insurers.

In 2008 the financial outlook is considerably better. On the one hand Eurotransplant expects to end the year with a positive result. Secondly a discussion was started with Eurotransplant’s financing authority leading to the conclusion that it should be assessed whether Eurotransplant’s budget matches the financial requirements of its National Mandates.

Therefore the financing authorities of all Eurotransplant Member States asked Eurotransplant to develop an analysis of Eurotransplant’s financial organization in relation to its National Mandates and to present a mid term strategic plan with a financial translation to be discussed during the upcoming budget negotiations. A project, named the Eurotransplant Policy planning (ETP) project is well under way to produce this analysis and mid term financial plan. The financing authorities currently form the project board of the ETP project.

An important conclusion of the analysis is that many of the services that Eurotransplant provides, are not explicitly mentioned in national contracts; i.e. frequent requests for data-analysis by individual centers. In the coming period the basic spectrum of services will have to be formalized. This means that services that are implicitly appreciated among the Eurotransplant community should be made explicit. So make yourself heard to us, to your national transplant Authority and to your National Transplantation Society.
What goals did we set and did we meet them?
The following 5 items have served as general points of focus for the last years and will remain to do so in the near future. There is no prioritization as each item is seen as an essential element. However for instance the implementation of ENIS-Q, the roll out of quality and safety management systems, the execution of the registry year plan 2008 are clear goals whereas increasing customer focus and incident reporting reflect a different way of working.

1. Strengthening ET’s internal organization
2. Improvement of the transparency and quality of ET’s services
3. Investigation of possibilities to increase ET’s donor pool
4. Acceleration of the development process of new allocation-algorithms
5. Enhancement of ET’s legislative and political position

1. Strengthening ET’s internal organization

Three days after last year’s user meeting, on the September 24, 2007, the Ministers of Health of the member states of Eurotransplant were invited and came to St. Gerlach near Maastricht. Together with the board and the directors of Eurotransplant three mayor results were realized:

- The signing of an affirmation document, in which the member states expressed their commitment to the Eurotransplant cooperative framework;
- The political commitment of the ministers to support Eurotransplant’s registry activities;
- The request by the ministers that Eurotransplant hosts a communication platform for the identification and exchange of best practices in the area of organ donation.

EUTIEP
Representatives from the Ministries of Health Care of the seven Eurotransplant countries came together in Leiden on June 18, 2008 to participate in a meeting hosted by the Board of Eurotransplant. During this meeting a platform to exchange information in the area of organ donation and transplantation was established. As a first step the platform is planning to identify best practices in the area of organ donation on a national level as well as best practices in the area of post-transplant registries on an international level.

The Eurotransplant community is pleased to be of help by hosting this platform, through which the member states can benefit from one another. Furthermore, the Ministries as well as Eurotransplant agreed upon that the European initiative on organ donation and transplantation is a subject of interest to all of us. Information exchange in this area continues to be important in order that whenever possible the member states in Eurotransplant will come up with a common opinion.

Enhancement of planning and controll
In October 2007, a new financial system was implemented leading to increased efficiency and accuracy of the processes related to Finance and Accounting. Some parts of the annual accounts 2007 were adapted compared to the annual accounts 2006. The annual accounts are now prepared in accordance with the Guideline for annual reporting 640 ‘Not-for-profit organizations’ of the Dutch Accounting Standards Board.

Extensive reporting & accounting activities
The webmaster, medical staff, helpline and many other co workers of Eurotransplant processed a substantial amount of information requests from national authorities, centers, individual doctors, patients and other parties. This number seems to be increasing. 2006: 493 - 2007: 556, until the first of October: 504.

These requests concern questions on transplant statistics, general on how Eurotransplant works, questions on the use of software applications, etc.
- Inspection by the German Inspection Committee The inspection committee of the Bundesärztekammer
- Audit by the Dutch Transplant Organization The Dutch Transplant Organization audited the quality system.
- Financial audit by accounting firm Naturally Eurotransplant's financial results were authorized by an external accountant

2. Improvement of the transparency and quality of ET’s services

Strengthening IT infrastructure
An important step in the improvement of the donor data flow to Eurotransplant is the fact that Austria, Belgium, Croatia and Slovenia have expressed their commitment and intention to implement electronic data exchange systems in order to communicate donor data to Eurotransplant electronically.

Benchmarking and harmonization
In order to improve our processes and quality systems, the contacts between UK Transplant and Scandiatransplant were further developed, among others with the aim of enabling benchmarking and exchange of best practices.

Eurotransplant's allocation process is currently undergoing a mayor overhaul. In the ENIS-Q project, the entire organ allocation process from donor reporting till registration of the transplantation is being scrutinized with the intention of eliminating manual steps wherever possible and adding process support to all manual steps that remain necessary.

In the area of system development and application management the following activities took place. In 2007, a total of 505 improvements (431 in 2006), bugs and new features where resolved for the different Eurotransplant applications. Also, extra effort went into reducing the
backlog on issues concerning the allocation of organs. A number of projects where initiated in 2007 and a number of projects was finished.

New technology
In conjunction with MELD the Service Oriented Architecture (SOA) was introduced in the IT-system. With both, BPEL (Business Process Executing Language) and SOA, the first steps to a more flexible IT are accomplished. The next application of BPEL will be in the ENIS-Q project from which in 2008 the first results will be delivered. This project (already started) aims to improve patient safety and transparency of the allocation process. This will be realized by integrating the process in to the new system so it can support the duty officers and implicitly log every detail of the allocation process.

3. Investigation of possibilities to increase ET’s donor pool

As everybody is aware of, Eurotransplant was enriched with the joining of Croatia last year. Also the coming years Eurotransplant intends to be open and look for opportunities with countries who would like to cooperate with us.

4. Acceleration of the development process of new allocation-algorithms

In order to enhance the flexibility and safety of our ENIS system, 2 proofs of concept upgrading of our ENIS-system have been conducted successfully. The 2 technologies also enable a better understanding and communication between the experts in the field and the developers.

Transparency & quality of services – process orientation and flexibilization
The first proof of concept actually has been followed up by incorporation in Model for End Stage Liver Disease (MELD) non-standard exception audit system, which was released December 1, 2007. The system allows end-users to request a non-standard exception MELD for their liver recipient. The request is then made available to the auditors who can answer the request, which leads to a higher MELD score or not. The complete process runs autonomously.

5. Enhancement of ET’s professional, legislative and political position

The main actions are developing a common data dictionary, defining a methodology and delineating legal & technical requirements for registry management. Furthermore a safety management program closely monitoring risks associated with the use of i.e. marginal donors will be designed. An agreed prototype for an organ vigilance system that is applicable in Europe will be defined, as well as a consensus document for a quality assurance system.

The project will yield a harmonization of data definitions, methods and technical requirements. This is a prerequisite for creating a pan-European registry for post-transplant outcome data. Ultimately this registry of registries will lead to a more efficient and safer organ allocation system.

At the end of my report I would like to draw your attention to the upcoming winter meeting that will be held in ALPBACH, AUSTRIA.

After 25 successful Winter Meetings in Fügen, it became obvious that time has come to breathe new life into the concept of this meeting. The ET Winter Meeting is and should continue to be complementary to the ET Annual Meeting in Leiden. This implies that it provides the possibility to communicate more intensively on certain topics in an informal atmosphere thus stimulating understanding between people, specialisms and nationalities. To achieve this, parallel sessions focusing on different current areas of interest are planned.

Furthermore, we intend to bridge generation gaps by offering workshops by renowned experts in the field to the young upcoming generation of the transplant community.

For the realization of this new concept a change of venue is considered to be essential.

Therefore the next ET Winter Meeting will be held from January 22 – 24, 2009 in the beautiful Tyrolean mountain village Alpbach in Austria with its modern congress center. Further details about the 2009 Winter Meeting – which will continue to be hosted by Prof. Günther Laufer - will be provided in the next issue of the ET Newsletter.

Thank you very much
Part two

**Eurotransplant**

**Medical Directors Report**

Axel Rahmel

Leiden, October 9, 2008

**Topics**

- Waiting list
- Donation
- Transplantation

**Kidney Waiting List and Transplants**

Eurotransplant 1969 - 2007

**Liver Waiting List and Transplants**

Eurotransplant 1995 - 2007

**Heart Waiting List and Transplants**

Eurotransplant 1995 - 2007

**Lung Waiting List and Transplants**

Eurotransplant 1995 - 2007

**Pancreas Waiting List and Transplants**

Eurotransplant 1995 - 2007

* Including kidney and liver transplants

**Donors reported in Eurotransplant**

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**Organ donation - Eurotransplant 2007**

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Topics

- Waiting list
- Donation
- Transplantation

Kidney Waiting List and Transplants
Eurotransplant 1969 - 2007

Heart Waiting List and Transplants
Eurotransplant 1995 - 2007

Pancreas Waiting List and Transplants*
Eurotransplant 1995 - 2007

Donors reported in Eurotransplant

Organ donation - Eurotransplant 2007
Report of the Eurotransplant Assembly

Report of the Eurotransplant Assembly on October 9, 2008 in Holiday Inn, Leiden, the Netherlands

Chairman: Prof. Dr. Günther Laufer
Secretary: Verena Diepeveen-Huijsman

The meeting is attended by 200 participants.

Opening
The chairman opens the meeting and welcomes all participants. Due to the fact that he himself is involved in the next agenda point ‘election of the chairman of the Assembly’, Prof. Laufer steps down and passes the chairmanship on to the Eurotransplant president, Priv. Doz. Dr. Bruno Meiser.

Election of the chairman of the Assembly
According to the Eurotransplant Articles of Association, the current chairman of the Assembly, Prof. Günther Laufer from Innsbruck (Austria) has to be (re)-elected. Since no other candidates had applied for this position and Prof. Laufer had declared to be available for another term, he is re-elected by the Assembly.

After his re-election, Prof. Laufer takes over the chairmanship from Dr. Meiser.

Election of four Board members A

Kidney section
According to the Eurotransplant Articles of Association, the current Board members A in the kidney section, Prof. Ferdinand Mühlbacher from Vienna (Austria) and Prof. Dirk Ysebaert from Antwerp (Belgium) have to be (re)-elected. Since no other candidates applied for these positions and both Prof. Mühlbacher and Prof. Ysebaert had declared to be available for another term, they are re-elected by the Assembly.

Liver section
According to the Eurotransplant Articles of Association, the current Board member A in the liver section, Prof. Karl-Walter Jauch from Munich Grosshadern (Germany) has to be (re)-elected. Since Prof. Andreas Paul from Essen (Germany) also applied for the position, a voting procedure takes place. Since the majority of votes are cast in his favor, Prof. Jauch is re-elected by the Assembly as the Board member A in the liver section.

Lung section
According to the Eurotransplant Articles of Association, the current Board member A in the thoracic (lung) section, Prof. Dirk Van Raemdonck from Leuven (Belgium) has to be (re)-elected. Since no other candidates applied for these positions and Prof. Van Raemdonck had declared to be available for another term, he is re-elected by the Assembly.

Announcement of the winner of the Henk Schippers Young Investigators award
The Assembly chairman invites Eurotransplant’s president, Priv. Doz. Dr. Bruno Meiser to announce the 2008 winner. Dr. Meiser announces that this time two candidates gained the same score as a consequence of which both of them are nominated as the winner.

- Dr. Meiser together with Mrs. Hanneke Siebers, the widow of the late secretary/treasurer, Henk Schippers, present
- Dr. Fleur Samantha Benghiat from the Institute for Medical Immunology of the Université Libre de Bruxelles, Charleroi, Belgium and
- Dr. Cyril Moers of the Department of Surgery – Transplantation & Organ Donation of the University Medical Center Groningen

with the 2008 Henk Schippers Young Investigators award. Dr. Benghiat and Dr. Moers are congratulated with this prize and are invited to present their data during the Eurotransplant winter meeting in Alpbach (Austria), January 2009.

The following presentations were also given during the Assembly. Since they will be published in one of the issues of the ET Newsletter, there is no need to further elaborate on these presentations in this report:

- Presidential address by Dr. Bruno Meiser
- Directors report by:
  Arie Oosterlee, general director
  Axel Rahmel, medical director

Prof. Laufer closes the meeting at 17:00 hrs by thanking all attendants for their participation in this informative meeting.
Summary of the meetings of the Eurotransplant International Board on October 8 & 10, 2008 in Leiden, the Netherlands

Ellen Houwaart and Verena Diepeveen, secretaries of the Eurotransplant International Board

Wednesday, October 8, 2008

The chairman welcomes the new secretary of the Board, Ellen Houwaart and says goodbye to the former secretary, Verena Diepeveen. The Board also says goodbye to the honorary president, Prof. Yves Varenrenghem and the Slovenian representative, Dr. Jasna Vončina, who both attend the Board meeting for the last time on a regular base.

The Board is informed about (the progress of) several projects:

Implementation of the ET general conditions
Approval of the general conditions by all ET national authorities is still pending for which reason they cannot yet be implemented. The reason that some national authorities did not yet approve the general conditions is related to some national laws that prohibit limitation of liability. Active approval rather than silent approval might strengthen the legal position of the general conditions. From this point of view, it is decided to address this issue during the meeting of the ET Information Exchange Platform (EuTIEP, Oct. 24, 2008) meeting as an attempt to convince national authorities. The Board furthermore decides that obtaining approval from all national societies by December 31, 2008 should be aimed at.

Progress on implementation of electronic donor data exchange
Currently, all but one ET countries send their donor data electronically which is expected to hold true for all ET countries by the end of this year.

Progress on hosting an ISHLT database by ET
Negotiations between ET and ISHLT are still going on. The ET directors explain to the Board that it was initially agreed upon that ET was only supposed to host the registry in order to gain insight into the quality of transplanted organs by looking at post-transplant results. The project, called European Framework for Evaluation of Transplant OrganS, is accepted by the EC and will be financially supported. The directors are congratulated with this accomplishment since this project is considered to be very important due to its scientific impact and also from a political point of view. It is regarded as another step in establishing ET as a leading organization and in consolidating its future position.

Visit of EU Commissioner for Health Affairs & Consumer Protection to the ET office
EU Commissioner Mrs. Androulla Vassiliou recently visited the ET office and was welcomed by the chairman and the directors. She was very supportive towards the EuTIEP as well as to the coordination by ET of the EC project for defining a post-transplant registry by ET.

Renewal of agreement between ET and Nederlandse Transplantatie Stichting (NTS)
A renewed agreement between ET and NTS was signed on October 9, 2008. The Board is informed that the renewed agreement covers the same tasks as the previous agreement. However, several matters have been described more specifically as well as explicitly.

The new Finance/IT manager of ET, Drs. Ton Valkering, is introduced to the Board.

The Board discusses the progress on implementation of already approved recommendations and expresses some concern about the rather long timeframe between approval and implementation. The directors explain the required amount of man-hours (IT as well as medical administration and staff) leading to prolonged implementation times but also inform that thanks to the introduction of new technologies the implementation of recommendations is expected to be sped up in the future.

Information on participation in European Commission (EC) project EFRETOS
The Board is informed that ET successfully took the lead in cooperation with several other European organizations in submitting a proposal regarding a project initiated by the EC in order to gain insight into the quality of transplanted organs by looking at post-transplant results. The project, called European Framework for Evaluation of Transplant OrganS, is accepted by the EC and will be financially supported. The directors are congratulated with this accomplishment since this project is considered to be very important due to its scientific impact and also from a political point of view. It is regarded as another step in establishing ET as a leading organization and in consolidating its future position.

With regard to ET’s financial situation, the directors inform the Board that they expect that the year 2008 will be ended with a slight positive result. The Board approves
two recommendations in relation to finance. One is the ET budget proposal 2009 (RFC02.08). The other one is related to a report by the external agency, Lokerse Consultancy. This agency is working together with the directors on ET’s policy planning project (2009-2013) [ETP]. The directors are given a mandate to use the current and future results of the Lokerse report in the budget negotiations with the German health care insurance companies (RFC03.08).

The Board is elaborately informed about the progress of the ETP. For the first phase of the project, Lokerse Consultancy achieved three milestones. First of all, they determined the current situation of ET, the 1st-situation. Secondly, a risk analysis was performed. Finally they developed a proposal for a new financial model, which could be used for budget negotiations.

A number of conclusions were drawn from the Lokerse report:

- ET country specific services mandated by national authorities should be made more transparent.
- ET is vulnerable because knowledge in some key areas is limited to only one or few experts.
- Establishment of a central communication function is strongly recommended.
- ET is in some areas underfunded;

In order to improve the organization Lokerse recommends to add personnel for project management, communication & registry and support of the directors. In addition it is recommended to raise funds for the allocation department, development of the IT department, housing and maintenance and the development of a budget for training and education of ET personnel.

The discussion on the ETP is concluded by the decision to form a task force consisting of the chairman, some Board members and the directors to develop recommendations for improving the internal organization based on the Lokerse report and develop recommendations for ET’s future strategy.

Reports of the ET Kidney Advisory Committee (ETKAC) and the ET Liver Intestine Advisory Committee (ELIAC) are discussed. Since these reports will be published in this issue of the ET Newsletter, there is no need to further elaborate on these reports in this summary.

The medical director brings up the issue of the role of donor profiles in allocation and inconsistencies in donor profiles. Sometimes donor information changes during the allocation procedure. The Board is unanimously of the opinion that ‘an offer is an offer’ (RET01.08). With regard to different profiles of patients listed for combined organ transplantation, the Board decides that the profile of the ‘leading organ’ will be used. Leading organ can be explained by the sequence in which organs are offered: Lung->Heart->Liver->Pancreas->Intestine->Kidney.

Next the chairman presents the report of the 1st meeting of the Exchange Information Platform (EuTIEP, June 18, 2008), where the representatives of the ET member countries in the Board and representatives from the national health ministries discuss current practices and problems with respect to organ donation. Furthermore, it is considered to be of upmost importance to establish an ET post-transplant data registry. In this regard a number of questions are raised by the EuTIEP members such as who is collecting the data, who is financing the project, who is owner of the data, etc. Finally, the EuTIEP achieves consensus on the necessity that ET sets up a registry.

Concerning the lung transplant cooperation between Vienna and several non-ET countries, it is decided to arrange a meeting in which the Austrian Ministry of Health, the Vienna University, Austrian Board members, the chairman and the ET directors will participate. The aim of the meeting is to achieve consensus about correct utilization of the ET non-resident policy.

During its previous meeting, May 2008, the Board partly approved the ET non-resident policy as proposed by the ET non-resident working group. At that time there was no consensus in the Board regarding the proposal of the working group to extend the 5% rule also to non-resident kidney and pancreas patients. The Board therefore decided that this proposal was first to be discussed by the ETKAC. In the meantime the ETKAC discussed this issue and concluded for several reasons not to be in favor of extending the 5% rule to kidney patients (see report of the ETKAC meeting of September 10, 2008 elsewhere in this Newsletter). The Board finally approves the ET non-resident policy with maintenance of the 0% rule for kidney and pancreas which implies that non-resident kidney and pancreas patients cannot be registered on the ET waiting list.

The selection committee of the Henk Schippers Young Investigators Award informs the Board that this year two applicants gained the same score. This resulted in two winners who will share the prize.

**Friday, October 10, 2008**

The Board congratulates Prof. Karl-Walter Jauch (liver section), Prof. Ferdinand Mühlbacher and Prof. Dirk Ysebaert (kidney section) as well as Prof. Dirk Van Raemdonck (lung section) with their re-elections as Board member A. Prof. Günther Laufer is congratulated with his re-election as chairman of the Assembly.

The Board evaluates the annual ET meeting. All meetings were well attended. The presentations at all users meetings as well as the Presidential Symposium / Assembly were of high quality. Besides the excellent presentations the Belgian royal decoration - Ridder in de Leopoldsorde – that was awarded to Prof. Yves Vanrenterghem was one of the highlights of the Presidential Symposium.

The Board considers the desirability of a rotation system of chairmanship of the ET Advisory Committees. It is con-
cluded that there is currently no need to change any of the chairmanships.

The ET Ethics Committee (ETEC), ET Pancreas Advisory Committee (EPAC) and the ET Thoracic Advisory Committee (EThAC) had meetings on October 9 and 10, 2008 in the framework of the annual ET meeting. The reports of these meetings will be published in the Newsletter.

The chairmen of the ETEC, EPAC and EThAC briefly report on their meetings:

The ETEC chairman reports that one of the main topics discussed was endorsement of the ‘Declaration of Istanbul’ in which organ trafficking and transplant tourism are condemned (REC04.08). This recommendation is approved by the Board.

The ETEC had raised some ethical questions with regard to the ET Senior DR-matching program (ESDP). The ETKAC chairman explained these questions during the ETEC meeting after which the ETEC gave a positive advice on the ESDP.

The ET Thoracic Advisory Committee (EThAC) also had a meeting, at which the main topic of discussion was improvement and rescheduling of the German thoracic allocation.

Most important topic of the ET Pancreas Advisory Committee (EPAC) was a discussion on the problem of patients, developing a kidney graft failure following kidney+pancreas transplantation who were denied for the kidney HU status by ETKAC auditors. Since the national societies rather than the ETKAC are the national institutions that decide on HU regulations, the EPAC formulated RPAC01.08.

Based on the conclusion drawn during the previous Board meeting on October 8, 2008 the Board approves RET01.08.

The Board is presented with an outline of the scientific program of the ET winter meeting that will take place in Alpbach, Austria from January 22 – 24, 2009. These days concern a Thursday, Friday and Saturday. Prof. Laufer, co-organizer of the winter meeting, states that in future years it is intended to return to the usual Wednesday, Thursday and Friday.

The scientific program consists of two blocks per day. On the first day presentations of opinion leaders and presentations of new developments are planned.

On the second day six workshops are scheduled in the first block, followed by reports of the workshops as well as lectures by keynote speakers in the second block.

Finally the Board discusses rules regarding data access and publication of ET presentations on the ET website. In the proposed rules regarding data access five groups of users can be distinguished: authorized ET users, public users, ET Board, ET Advisory Committees and national authorities. For each group the accessibility level to data is described: patient, center and country level. The proposed regulations for data presentation on the ET website are based on the proposed rules regarding data access. The Board approves the rules as proposed by the ET directors. It is expected that putting these data on the public site will reduce the number of external requests and as a consequence reduce the workload for ET.

The Board is furthermore presented with a proposal for a practical approach to prioritization and authorization concerning data analysis. This approach is based on a categorization of requests in three levels indicating the workload involved, the inquirers relation to ET and the expected period of time in which data requests will be dealt with. The Board postpones a decision on the approach document until after having received a cost calculation per level.

The Eurotransplant Duty Office can be reached 24 hours per day at 0031 71 5795795.

Please note that all phone calls to the Duty Office and the Medical Staff are logged and recorded. Recording of these conversations is in accordance with Dutch Law.
**KIDNEY ADVISORY COMMITTEE**

**RKAC02.08**
Kidneys should be allocated to AB0 identical recipients. Exception should be made for:
- The acceptable Mismatch (AM) program: kidneys should be allocated to AB0 compatible recipients;
- Combined organ recipients: kidneys should be allocated according to the AB0 blood group rule of the leading organ;
- Rescue allocation: selection of recipients should preferably be AB0 identical.
The effect of these changes should be evaluated after 5 years.

**RKAC03.08**
Recipients suffering from end stage renal disease after having donated one of their own kidneys, are eligible for pre-emptive listing on the kidney waiting list. The recipient will be granted an allocation bonus of 500 points upon listing.

**LIVER ADVISORY COMMITTEE**

**RLAC02.08**
In case an HU patient enters the waiting list during a running allocation procedure prior to the acceptance of the donor organ by a transplant center, the decision of the center that currently has the patient oriented first offer has to be waited for. If the organ is not accepted, the donor organ shall as a next step be offered to the new HU patient (if according to a new match run, this patient would now have a higher or identical rank position to the patient for whom the offer was just turned down).

**PANCREAS ADVISORY COMMITTEE**

**RPAC01.08**
In case of kidney failure after pancreas transplantation with pancreas bladder drainage but functioning pancreas, the recipient is eligible for the HU status for a kidney transplant.

**ETHICS COMMITTEE**

**REC04.08**
The ETEC recommends the Board to officially endorse the 'Declaration of Istanbul' (on organ trafficking and transplant tourism) and to develop steps to implement it inside the ET community.

**FINANCIAL COMMITTEE**

**RFC02.08**
Recommend to the Board to authorize the ET budget proposal 2009, which is essential for the director’s mandate to lead the organization after January 1, 2009.

**RFC03.08**
Recommend the Board to give a mandate to use the current and future (milestone IV) results of the ETP project in the upcoming budget negotiations with the German health care insurance companies (Krankenkassen) in order to secure the necessary budget with which ET can develop and execute its future strategy. It is suggested that the Directors work closely together in the preparation of this framework with the President and Treasurer of the Board. It is important to be aware that our negotiating partner, the German Krankenkassen are currently in a phase of rapid transition, for which reason it is considered to be very essential to conduct budget negotiations - in which the results of the ETP project are included - before the end of 2008.

**EUROTRANSPLANT INTERNATIONAL BOARD**

**RET01.08**
If new / updated match relevant donor information becomes available to ET after the offering procedure has started, the center that already has accepted the offer or that currently has the first offer is made aware of the new information. The center can then decide – independent of the predefined patient- and/or center-specific donor profiles – to keep / accept the organ for the patient selected based on the initial match list.

If the organ is given back or the first offer is not accepted, a new match list is generated based on the new / updated match relevant donor information and the allocation is continued based on this new match list.

After the matching has been performed at the ET office, changes in patient- or center-specific donor profiles are not taken into account in this allocation procedure anymore (unless a new match has to be performed later, based on the above mentioned criteria).
The following reports from the Advisory Committees were discussed by the Eurotransplant International Board on October 8 and 10, 2008 in Leiden, the Netherlands

Report of the 32nd meeting of the Eurotransplant Kidney Advisory Committee (ETKAC)

Chairman: Prof. Dr. J. de Fijter
Secretary: Dr. J. de Boer

The ETKAC met on Wednesday, September 10, 2008
Members present: 11 + 1 external advisor + 1 director
Members excused: 5

A. Progress on study protocol Eurotransplant Senior DR compatible Program (ESDP)

The progress of the ESDP study was extensively discussed. The Eurotransplant Ethics Committee (ETEC) still has some questions about the fairness of the study towards recipients who do not want to participate in this study. Answers to these questions will be formulated. In addition the ETKAC chairman will explain the ETKAC point of view at the ETEC meeting on October 10, 2008.

B. AB0 kidney allocation

The current AB0 blood group rules were discussed. Especially AB0-0 recipients are in disadvantage, leading to accumulation of AB0-0 recipients on the waiting list and consequently waiting time for AB0-0 recipients. It seems unfair towards this group of recipients to allocate to other AB0 blood group recipients. Therefore the ETKAC formulated RKAC02.08

C. Pre-emptive kidney transplantation

As requested by the Board, the ETKAC reconsidered a recommendation on pre-emptive transplantation which was in first instance approved by the Board and withdrawn in a later stage (RKAC02.03). The ETKAC is of the opinion that the renal function, in contrast to the onset of dialysis, is almost not to control uniformly by any audit. Therefore the ETKAC would not like to re-institute RKAC02.03.

D. Age matching in kidney allocation

The ETKAC was presented with interesting data regarding age matching. These data resulted in the decision to work on a detailed proposal for age matching in kidney allocation.

E. Evaluation of current cross border kidney allocation

The ETKAC was presented with data showing differences in CIP between locally and cross border exchanged kidneys. The ETKAC decided to perform a multi-variate analysis on the effect of cross border exchange.

F. Allocation priority for living donors

As requested by the ETEC, the ETKAC discussed the topic of living kidney donors coming into need of an organ transplant themselves. The ETKAC acknowledges that these recipients should get some kind of priority in kidney allocation. Therefore the ETKAC formulated RKAC03.08.

G. Establishment of a 5% rule for non-resident kidney recipients

As requested by the Board, the ETKAC considered extension of the 5% rule for non-resident kidney recipients. Due to the fact that kidney transplantation is neither a very complex technical procedure nor a life saving procedure, the ETKAC is not in favor to extend the 5% rule to kidney patients. Another argument against allowing non-residents on the ET kidney waiting list would be that such a measure would take away any incentive to develop a kidney transplant program in the countries concerned. In addition it might lead to double registrations of recipients which cannot be monitored. Therefore the ETKAC decided that establishing a 5% rule for non-resident recipients is not desirable. The ETKAC will however elaborate on defining exceptions for cases in which non-residents could be accepted on the kidney waiting list.

H. Study proposal on 'The DRIP study'

The study concerns highly immunized recipients who will be pre-treated before transplantation with plasmapheresis and an immunosuppressive drug. If desensitization is successful, kidney transplantation should follow within a short timeframe. Therefore the ETKAC was requested to grant these recipients the HU status. The ETKAC is in favor of granting the HU status for recipients entered in the study, precluded that a limited number of recipients (maximum 10) will be taken into account.
I. Priority for recipients awaiting a kidney transplant after non-renal solid organ transplantation

Following a request from a thoracic transplant team the ETKAC discussed giving priority for recipients with renal failure after a thoracic organ transplant. The ETKAC is of the opinion that also other high risk groups could be defined for whom priority might be claimed (e.g. diabetic recipients). Therefore the ETKAC is not in favor of giving priority to this group of recipients. However, granting the HU status to high risk group recipients could be considered on an individual basis.

J. Indications and audit procedure for the kidney HU status

The ETKAC is of the opinion that an HU request for the indication ‘psychological problems with high risk of suicide’ can easily be audited by the ET medical staff, precluded that it is accompanied by a letter from a competent psychiatrist stating this risk. All other indications are less clear to define and will be forwarded to the ETKAC auditors.

Report of the meeting of the Eurotransplant Liver Intestine Advisory Committee (ELIAC)

Chairman: Prof. Dr. X. Rogiers
Secretary: Dr. A. Rahmel

The ELIAC met on Thursday, September 11, 2008
Members present: 8 + 1 ET representative
Members excused: 3

A. Reports from the national ELIAC representatives

The description of a specific case by the Belgian representative resulted in a vivid discussion on changing donor profiles during a running allocation procedure. This case concerned a Belgian extended criteria donor (ECD) for which ET refused the request to re-run a match with a modified donor profile in order to be able to still transplant a Belgian patient. The medical director explained – according to another recent case - the reason why ET is strict in not allowing changing donor profiles which reason is to avoid setting precedents.

The ELIAC discussion focused on two aspects:
- The question whether entered donor profiles are binding. The ELIAC members are unanimously of the opinion that these are binding for regular offers but not in case of center offers.
- The role of donor profiles, especially the awareness of ECD criteria. The ELIAC decided on measures to improve the awareness among transplant centers.

B. Refined analysis of death on the waiting list and HU offers

The ELIAC members were presented with an in-depth analysis – based on a UNOS methodology - on the mortality on the waiting list. This analysis showed a considerable drop in mortality on the waiting list over the past years independent of and prior to the introduction of MELD as an allocation tool. Detailed analysis shows that this drop was not due to a decrease in the absolute number of patients dying on the waiting list, but rather by an increase in the size of the waiting list.

Next a competing risk analysis showing the probability of a post-mortem liver transplant on the one hand and the probability of death on the liver waiting list was presented. These data clearly show the following (expected) effects of allocation using the MELD score: immediately after listing the chance to receive a donor organ increases, because the patients with a high MELD score quickly receive a donor organ. This rapid allocation of donor organs to patients with a high MELD score leads to the significant drop in mortality on the waiting list in the early phase after listing for transplantation.

On the other hand the current analysis also shows that the number of patients who have to wait very long (several years) is increasing. Although the relative mortality (number of death per patients waiting) in this long waiting is low, the absolute number of deaths is now increasing because the number of patients at risk is increasing. The ELIAC asked ET to monitor the developments in this area.

The ELIAC decided that by the beginning of 2009 a questionnaire will be developed in order to analyze the early results of liver allocation after the introduction of MELD.
The ELIAC was furthermore presented with an analysis of HU requests. The median waiting time of two days for patients in HU status in spite of the quite high number of HU transplants is regarded as an indicator for the ongoing effectiveness of the HU concept. Another part of the analysis concerned the rate of turned down offers for patients in HU status. The ELIAC is of the opinion that – especially taking into account that for HU patients livers are offered without taking the recipient-specific donor profile into account – the number of turned down offers is acceptable.

The duration of HU status of all patients (except one) was below two weeks, again showing the effectiveness of the allocation system but this is also considered as an indicator that there is no substantial misuse of the HU system.

C. Current problems regarding HU liver allocation

The discussion on this issue focused on three aspects:

1. Allocation rules including blood group rules within the HU procedure

A liver from an AB0-0 donor was transplanted into an AB0-A HU recipient and the transplant center had suggested to open the blood group rules for HU recipients, possibly linking this opening to specific conditions (no suitable offers within a given number of days). The second case was closely related, this time the transplant center had asked to auditors to allow a change of the blood group rules for HU patients (adult liver to pediatric recipient AB0-0 to AB0-A).

The ELIAC members were of the opinion that the role of the auditors is to identify patients that fulfill HU criteria. Auditors must not and cannot change allocation rules.

Following the results of the HU analysis presented, the ELIAC members agreed not to change the blood group rules for HU recipients. Reasons for that are:

- The current blood group rules are already wide and take care of all patient groups.
- Analysis shows that median waiting time is very short for these patients already now.
- Widening of the blood group rules would result in further disadvantage for AB0-0 recipients who already now have to wait longer than recipients with other blood groups.

2. Allocation sequence in case of a new HU recipient during a running allocation procedure

It repeatedly happens that prior to the transplantation of an organ allocated via ET an HU recipient newly enters the waiting list. Shall this organ then be offered to this HU recipient (if according to a new match list he would be eligible for the offer and have a higher rank position than the current selected patient)?

The discussion on this issue resulted in the formulation of RLAC02.08 (see first page).

2. Reachability of auditors

ET reported that in recent months there have been repeatedly problems to reach auditors for HU liver requests. The ELIAC members together with the ET representatives agreed upon measures to improve the audit process.

D. Logistical aspects of the ET split liver procedure

The ELIAC was presented with a German problem regarding split liver allocation. The problem concerns the fact that centers only decide in such a late stage to split or not to split that the available extended right lobe (ERL) of the liver can only be offered as a rescue offer. The non-German members stated to be of the opinion that such country specific problems should be discussed with the national representatives directly rather than in this meeting. The German members recommended to prospectively make reserve offers according to the ERL match list in case a liver from >70 kg donor is offered to a >35 kg recipient.

The ELIAC members furthermore expressed their concern about the decrease in split liver transplantation in general and of in-situ splits in particular.

E. Predictive model for liver graft failure after liver transplantation: research of the ET data base – research protocol by the Leiden University Hospital

The ELIAC was in general of the opinion that this study should be supported and performed in close cooperation between the LUMC and ET. Prior to the start of the study two questions have to be addressed:

- The more fundamental question of the data ownership, the feeling of the ELIAC is that the data belong to the ET community and that ET is responsible for the adequate use of the data. A policy similar to the policy of e.g. the ELTR should be used in conjunction with the use of the data by external parties including clear publication rules;
- The scientific question of the accurateness of the selected parameters for the planned analysis.

F. Request for patients with pseudomyxoma peritonei by University Hospital Tübingen: NSE or ‘standard’ ACO

Two aspects of this proposal were discussed: is the idea to perform a study to test an opening of the indication for multivisceral transplantation warranted? And if yes, should the patients be prioritized and in what way (‘Non Standard Exception’ [NSE] as suggested in the study pro-
posal or ‘Accepted Combined Organ transplantation’ [ACO] status, which would give these patients high priority)?

All ELIAC members were quite sceptical concerning the study proposal. Especially in the light of the severe organ shortage, such a widening of the indication for multivisceral transplantation with only limited probability of success make them reluctant to support this study. The ELIAC decided to first have the study investigator ask the local ethics committee for a statement. After having received this statement, the German ‘Organkommission Leber’ will have to make up its mind whether an NSE status can be granted. The ELIAC was unanimously of the opinion that an ACO status should not be granted.

G. Allocation priority for living donors

On request of the ETEC, the ELIAC discussed REC02.08 on priority for living donors. There was quick agreement among the ELIAC members that a living donor shall be granted HU status in case of acute liver failure directly related to the living liver donation procedure independent of the point in time when the liver failure occurs (within or outside the 14 days window). It is even considered to give these patients higher priority than other HU patients.

There was however discussion and controversy within the ELIAC about other cases with regard to living donors who become patients. The discussion was concluded by the decision to present the current ideas to the ETEC members and to ask for their input.

B. Pancreas allocation after three medical declines

The EPAC was informed that, on request of some Belgian centers, a vascularized pancreas will after three medical declines, first be offered to the donor center prior to switching to islet allocation. In the former situation it was immediately switched to islet allocation after three medical declines of the vascularized pancreas.

C. Discussion on analysis of indications for SU requests

Based on an in-depth analysis of SU requests presented, the EPAC concluded that there is no reason to change the current time frame of 14 days in order to get a renewed SU status after graft failure.

In this respect the EPAC discussed a question from the ET medical staff how to deal with SU requests that are submitted due to graft failure after two weeks. The EPAC decided that such requests will not be audited by the ET medical staff but that these requests are to be submitted to the pancreas audit committee.

A second conclusion of this in-depth analysis is that the EPAC is in favor of a 3 months time limit of the SU status for vascularized pancreas.

D. Discussion on HU kidney status after pancreas transplant failure

Since the BÄK decided that the HU kidney status is only granted if there is a life threatening situation due to kidney failure, there is no adequate way to treat recipients with a kidney failure after having received a pancreas transplant with a bladder drainage. The EPAC decided that in these specific cases an exception should be made (RPAC01.08).

E. 5% Rule for non-resident kidney and pancreas patients

The EPAC was informed that the ET non-resident working group had proposed to the Board to extend the 5% rule to kidney and pancreas patients which is currently 0%. Since no consensus was achieved in the Board, the ETKAC was asked to discuss this issue. The ETKAC concluded to be in favor to maintain the current rule. After the ETKAC explanation the Board supported the ETKAC conclusion and approved the proposed ET non-resident policy with maintenance of the 0% rule for kidney and pancreas. The EPAC decided to be in line with the ETKAC conclusion but will put forward a slight distinction in case the discussion on this issue should ever be re-opened.
Report of the meeting of the Eurotransplant Thoracic Advisory Committee (EThAC)

Chairman: Prof. Dr. G. Laufer
Secretary: Dr. J. Smits

The EThAC met on Thursday, October 9, 2008
Members present: 13 + 1 director + 1 external advisor
Members excused: 1

A. Status new thoracic allocation policy in Germany

The EThAC was informed by the German external advisor that in Germany a working group had been established that prepared an allocation scheme which is still in a very preliminary phase as there does not yet exist consensus for this scheme. Besides that the current proposal is bound to face serious legal objections as the proposal incorporates a quota system for listing very sick patients.

B. Establishment of guidelines for thoracic organ procurement

The EThAC was presented with guidelines for thoracic organ procurement drafted by a former EThAC member. The draft will be discussed by the OPC after the EThAC members have given their comments.

C. Priority for recipients awaiting a kidney transplant after non-renal solid organ transplantation

This topic was discussed based on a discussion in the ETKAC regarding a request from a center to assign priority to recipients listed for a renal transplant after a non-renal solid organ transplantation. The ETKAC concluded that the current rule – no priority for this category of patients - should not be replaced. However, granting the HU status to high risk patients could be considered on an individual basis.

The EThAC did not support the ETKAC’s point of view to consider patients on an individual basis. However, prior to asking the ETKAC to reconsider this issue, actual data on the incidence of ESRD and mortality of patients who become renal insufficient after heart / lung transplantation will be investigated by the EThAC.

D. EThAC proposals for the scientific program of the ET winter meeting 2009

The EThAC suggested to dedicate a workshop to the issue of an allocation scoring system.

E. Agreement ISHLT-VAD Registry

The EThAC was informed about the need for an international registry for mechanical support devices that, on request of the ISHLT, should be hosted by ET. However, the ET medical director informed that a prerequisite for a commitment to host this registry is full cooperation of large VAD programs. The EThAC will be informed on further progress of the negotiations with the ISHLT.

F. Progress regarding pilot on thoracic allocation scoring systems

The EThAC was informed that the 4 major lung transplant programs in ET have explicitly stated to participate in this study to evaluate the use of the UNOS Lung Allocation Score in ET. In the coming period a study group will be set up whose first task it is to write a study protocol.

G. Results of the survey among HU auditors

The results of a survey among HU auditors regarding HU request forms, HU criteria and HU workshops was presented and summarized. The responding auditors consider the criteria useful but are of the opinion that an update would further improve their tasks; the workshops are well received and should be continued emphasizing on case discussions. This resulted in the establishment of a working group, consisting of EThAC heart as well as lung auditors, that will take care of adapting HU criteria and HU request forms.

The EThAC furthermore agreed upon the establishment of a ‘code of conduct’ for HU auditors. However, prior to implementation of such a code, legal constraints should be carefully studied. A draft version will be presented at the next EThAC meeting.

Report of the meeting of the Eurotransplant Ethics Committee (ETEC)

Chairman: Prof. Dr. P. Schotsmans
Secretary: Dr. A. Rahmel

The ETEC met on Friday, October 10, 2008
Members present: 8 + ETKAC chairman
Members excused: 0

A. ETKAC answers to ETEC questions with regard to ET Senior DR-matching Program (ESDP)

The ETEC members had some questions regarding possible disadvantages for patients not participating in the study and regarding the issue of informed consent by patients.
After the ETKAC chairman and the medical director/ETEC secretary had given a very detailed explanation of the allocation algorithm, there is immediate agreement to the proposed ESPD study protocol by all members of the ETEC. Their main concern that patients who are not participating in the study will be put at disadvantage by the allocation scheme had been taken away.

B. Discussion on statement regarding ETs condemnation of organ trafficking and tourism

The ETEC unanimously supports the idea that the Board of ET endorses the 'Declaration of Istanbul' on organ trafficking and transplant tourism which was already endorsed by several larger international transplant societies and other stakeholders. The ETEC members were furthermore of the opinion that the ETEC should also develop some ideas or recommendations on how the policy of the Declaration of Istanbul can in fact be implemented in the ET community. Such a plan should include concrete suggestions for the transplant centers which actual steps could be taken. Based on this discussion a recommendation to the Board was developed (REC04.08).

C. ET's role in offering or not offering donors with tumors

The ETEC was informed that an analysis revealed that the number of donors having a tumor at time of offering to ET is extremely low. The number is actually lower than expected. Organs from this type of donors are only allocated within the ET framework to patients who have given consent for such types of organs.

Therefore this specific criterion is documented in the ENIS computer system and also taken into account in the process of the organ allocation. A document of the Council of Europe concerning tumor diseases is taken into account in the daily work of the ET doctors so that in case of a high risk tumor the doctors can immediately get in contact with the procuring organization and/or surgeon to discuss whether the organs should really be further allocated. ET does not take the decision to stop the allocation of a tumor-positive donor by itself, but only in close cooperation with the organ procurement center / surgeon. The ETEC supported this approach but asked for continuous monitoring of the number of tumor-positive donors being offered to ET in order to see whether this is an increasing problem and whether further steps / actions have to be taken.

D. ELIAC questions regarding REC02.08 on priority for living donors

The ETEC was informed that both the ETKAC and the ELIAC discussed REC02.08 considering how to implement rules based on this recommendation. The ETKAC came to the conclusion that a donor for kidney shall be given priority similar to HU patients which is getting a bonus of 500 points. In addition pre-emptive listing on the waiting list is allowed. The ETEC is of the opinion that it is not up to them to judge on the contents of the proposal of the ETKAC but that they see this proposal as being absolutely in agreement with the general statement of REC02.08 and that they appreciate the efforts taken by the ETKAC.

The ELIAC also discussed whether a previous living donor shall only get preference for the type of organ they donated or also for other organs. The ETEC members clarified that in their mind the advantage for a living donor should be dependent from the type of organ being donated but also extend to other organs if the organ failure of this not donated organ is linked directly to the donation procedure. This procedure was also supported by the ET Board.

Next the ETEC was presented with ELIAC ideas on prioritizing patients:

- In case of acute liver failure after a liver donation procedure, the donor shall be granted an HU status even if this acute liver failure takes place later than 14 days after transplantation as long as it is in direct conjunction with the donation procedure. The ETEC strongly supports this extension of the HU rule.
- The ELIAC has discussed two options giving preference to patients who have liver failure late after liver donation. The ETEC keeps the decision on the practical implementation of course to the ELIAC, from an ethical point of view, taking also into account the transparency and reliability of the process they suggest that the model of granting 40 MELD points is the most straightforward option. Finally, the ETEC agrees to the view of the ELIAC that it is not necessary that the patient has to prove that the liver failure that is occurring years after the donation is really related to the donation procedure but that in any case the benefit of doubt shall be given to the donor.

E. ETEC proposals for scientific program of ET winter meeting 2009

The ETEC members were informed about the new concept of the ET winter meeting. They were of the opinion that for the 2009 winter meeting there should not be a workshop already, but they would be very much in favor of having one topic on ethical questions in one of the plenary sessions. However, ethical workshops are also to be considered for future winter meetings as well as ethical sessions during the annual ET meetings.

F. Miscellaneous

The ETEC decided to discuss at one of the future ETEC meetings what is needed to have a successful pediatric transplant program from an ethical point of view.
General information
The Administration Helpdesk can be reached from Monday till Friday from 8:30 am – 12:00 am and from 13:00 pm – 16:00 pm. By phone or e-mail:
For all questions you can reach us bij e-mail: administration@eurotransplant.nl
For urgent questions you can also reach us by phone 0031 71 5795795.

The helpdesk is managed by Frauke Horstmann, Margitta van Kasterop, Karin Rosdorff, Anne Marie Ramsoebhag and Ellis Rutgrink.

In the upcoming months the helpdesk will be closed on the following days:
2008
December 25th and 26th closed whole day,
December 31th closed from 12:00 pm.
2009
January 1st and 2nd closed whole day.

Meeting
During the Eurotransplant meeting on 9 and 10 October we were happy to meet some of the ENIS users. We answered various questions, for instance:

Q: How can I find which will be the upgraded MELD score for a Standard Exception?
A: In the ELAS Manual, chapter 05, you can find the initial MELD score per Standard Exception stratisfied by disease (5.8) or in addendum A - standard exceptions lists per country. The initial MELD score is expressed in % of the 3 month mortality equivalent.
In addendum B you can find table 5.11.2. This table shows which MELD score represents the xx% of the 3 mo-mortality equivalent.

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<thead>
<tr>
<th>MELD score</th>
<th>3-mo mortality</th>
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<td>20</td>
<td>10%</td>
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<td>22</td>
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<td>26</td>
<td>30%</td>
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</tbody>
</table>

If the initial 3 mo- mortality was 10%, in the table you can find that this resembles a MELD score of 20. After reconfirmation the upgrade is for instance 10% of the 3 mo- mortality equivalent. Now you add the initial 10% and the extra 10% after the 90 days reconfirmation. The recipient will receive a meldscore which resembles a 20% 3 mo- mortality equivalent. This is a MELD score of 24.

Q: Is there an easy way to quickly find something specific within the ET or the ENIS manual?
A: In every chapter of these manuals you can quicksearch on (key)words. Just fill in the (key)word in the search box and press enter.

Search for instance the keyword “pediatric”. Type the word into the checkbox and press the enter button. This forces a jump to the first page were the word “pediatric” is standing. The word is highlighted in blue. Whenever you click on the next button there will be a jump at the next line or page where this word is standing. This little trick works for more applications. If you don’t have a searchbox available simply click CTRL + F together and a searchbox will pop up. You can search on every webpage or document. You can also search this way within submitted ENIS reports. For instance as (key)word the ET-number.
Donordata.eu
During the ET-meeting the extra possibilities of donorreports via donordata.eu were presented. We would like to explain how you can use these new features:

During the allocation process:
- As a recipient center you can use donordata.eu to see the donorreport. You can also check if there is any update available concerning the offered or accepted donororgans. You can find this clicking the tab “Donor”.

During the follow up:
- The donor coordinator can view on tab “Recipient” all recipients transplanted with his donor. Available are recipient center, organ, waiting since, primary disease and age. For instance donor from BLATP, recipients from BLATP, BLMTP and GESTP:

- The recipient center can view on tab “Recipient” for his own recipient the same data as before (waiting list, immunological and recipient report are available for download), for recipients from other centers he can now view ET-nr., center and organ. From the same donor as above the recipient center GESTP can view:

Access donordata.eu
- You can access to donordata.eu as long as you have a connection to the internet. You need your username and logincode for donordata.eu. Simply go to www.donordata.eu/xxxxxx. The xxxxx resembles the donornumber. After you have logged in, the requested donorreport will open immediately.

- If you already have a account for the membersite but not for donordata.eu, you can fill in the register form on www.eurotransplant.eu. Fill in the mandatory fields and tick the checkbox for donordata.eu.

- If you register for access to the membersite for the first time, don’t forget to tick the checkbox for donordata.eu. See above.

- It is also possible to register only for donordata.eu.
Interview between Dr. Arie Oosterlee and Prof. Dr. Rutger Ploeg

Oosterlee: What is the prize and what is it stands for?
Ploeg: The prize is an award for outstanding clinical investigator ship in the area of organ preservation over the past years resulting in the Eurotransplant machine preservations study.

Oosterlee: What does the prize mean for Eurotransplant?
Ploeg: Personally he always appreciated it when a member of the Eurotransplant Community would win such a prize. For someone who started at Eurotransplant as a student and later became a Transplant Coordinator, a Transplantation surgeon and currently contributing to the international community in Advisor Committees and the Board. Even more important than the personal perspective is the fact that this study was realised also due the cooperation within Eurotransplant with Staff of Eurotransplant as well as the fact that this study was relevance for the day to day practise within Eurotransplant. In the perspective that Eurotransplant wants to become more and more active as a facilitator of clinical trials this study also carries importance.

Because of the persistent organ shortage more and more often organs are used from more marginal and even non-heart beating donors. Due to this shift of type of donor the current practice of static cold storage is not always sufficient anymore. This research has proven that Machine perfusion is overall and also for this specific subgroups a superior form of preservation leading to a more swift recovery of function.

Oosterlee: Will there be a sequel to this research?
Ploeg: The current group of clinical investigators has conducted in parallel to this study also a randomised trial in which the effect is assessed of machine preservation on extended criteria donors and non-heartbeating donors. In addition there is currently a cost effectiveness study on the way and there are a number of a more specific and supplementary questions that are being looked into in the area of flow/resistance management as well as the role of new bio markers for the monitoring of organ damage during machine preservation.

Eurotransplant wishes you a

Prosperous New Year