

# EUROTRANSPLANT newsletter

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## Introduction

Dear reader,

With great pleasure we offer you our new edition of the Eurotransplant (ET) Newsletter. You might notice it has increased in size compared to previous editions as we decided to combine our winter and spring issue. In this copy you will thus find even more updates for professionals in organ donation and transplantation on what is happening inside and around ET in these challenging and moving times.

The year 2012 had both high- and lowlights for all of us in the ET region. From my point of view, highlights certainly include the good performance and progress being made towards full membership by our preliminary member country Hungary. Also, the increase in donor numbers in Croatia, the Netherlands and Slovenia in the past year are certainly very positive news for patients on our waiting lists. A serious lowlight and concern to all of us are of course the cases of manipulation in various German transplantation centers and as a consequence, the loss of public confidence and decrease in donor numbers. From Leiden, we do

our utmost to support authorities by providing data necessary for audits and inspections and we continue being accountable and available to authorities, journalists and transplant professionals for answering questions and clarification of our procedures and activities.

In this issue of the ET Newsletter you will find detailed information on recommendations and policies that were approved during our recent Board meetings as well as of the presentations during our well attended Annual and Winter Meetings. You will also find reports of the meetings of our Advisory Committees. On page 2 of this Newsletter you will find the monthly statistics as usual. Comprehensive statistics however are available in our new online statistics library. In this Newsletter you are informed in detail about this statistics library.

We hope you find this ET Newsletter again informative and pleasant to read. Should you wish to comment on the contents, please do not hesitate to contact us whenever you have questions or require additional information.

Eurotransplant Newsletter is a publication of the Eurotransplant International Foundation. The Eurotransplant communication department welcomes articles pertaining to organ donation, allocation and transplantation. If there are issues you would like to be discussed and/or presented in the Eurotransplant Newsletter, please send copy to [communication@eurotransplant.org](mailto:communication@eurotransplant.org) Eurotransplant, P.O. Box 2304, 2301 CH Leiden, the Netherlands



# Statistics

PRELIMINARY CUMULATIVE STATISTICS EUROTRANSPLANT : JANUARY 01 - MARCH 31

## NUMBER OF ORGANS USED FOR TRANSPLANTATION, FROM DECEASED DONORS REGISTERED IN PERIOD

	Donor country	Austria	Belgium	Croatia	Germany	Hungary	Luxembourg	Netherlands	Slovenia	Non ET	Total
2013	Kidney	78	120	63	395	3	3	117	18	2	799
2012	Kidney	114	100	33	488	-	-	111	22	-	868
2013	Heart	18	17	7	86	7	1	8	6	2	152
2012	Heart	19	15	6	88	3	-	9	9	2	151
2013	Liver	29	78	33	208	5	2	36	7	3	401
2012	Liver	39	55	22	238	-	-	34	13	3	404
2013	Lung	32	54	4	154	13	2	42	8	13	322
2012	Lung	27	53	8	143	16	-	41	2	20	310
2013	Pancreas	5	6	2	28	-	1	4	1	-	47
2012	Pancreas	5	12	6	39	-	-	13	2	-	77

PRELIMINARY CUMULATIVE STATISTICS EUROTRANSPLANT : JANUARY 01 - MARCH 31

## NUMBER OF TRANSPLANTS PERFORMED, FROM DECEASED DONORS REGISTERED IN PERIOD

	Transplant Country	Ki	BKi	Li	SLi	Pa	Ki + Pa	He	BLu	SLu	He + BLu	Li + Ki	SLi + Ki	Li + Pa	He + Ki	Total
2013	Austria	68	2	23	-	1	3	16	31	1	-	1	-	-	1	147
2012	Austria	112	2	39	-	-	4	17	36	1	-	-	-	-	1	212
2013	Belgium	119	-	61	-	4	3	17	21	1	-	5	-	1	-	232
2012	Belgium	101	1	44	-	9	2	12	27	2	1	5	-	-	-	204
2013	Croatia	64	-	31	-	-	1	5	-	-	-	1	-	-	-	102
2012	Croatia	28	-	20	1	-	2	8	-	-	-	-	1	-	-	60
2013	Germany	354	1	198	29	1	28	87	79	12	3	4	2	-	1	799
2012	Germany	419	10	240	5	6	42	88	64	10	1	2	-	-	1	888
2013	Hungary	3	-	1	1	-	-	9	-	-	-	-	-	-	-	14
2012	Hungary	-	-	-	-	-	-	2	-	-	-	-	-	-	-	2
2013	Netherlands	119	-	35	2	-	3	7	20	-	-	1	-	1	-	188
2012	Netherlands	98	2	30	3	3	9	10	17	5	-	-	-	-	-	177
2013	Slovenia	11	-	4	-	-	1	5	-	-	-	-	-	-	-	21
2012	Slovenia	11	-	14	-	-	-	9	-	-	-	-	-	-	-	34
2013	Non ET	-	-	-	-	-	-	1	-	-	-	-	-	-	-	1
2012	Non ET	-	-	-	-	-	-	1	-	-	-	-	-	-	-	1
2013	Total	738	3	353	32	6	39	147	151	14	3	12	2	2	2	1504
2012	Total	769	15	387	9	18	59	147	144	18	2	7	1	-	2	1578

He-Heart   Ki-Kidney   Pa-Pancreas   Li-Liver   SLu-Lung   BKi-both Kidneys   BLu-Both Lungs   SLi-Split Liver

# Summary of the meeting of the Eurotransplant International Board on Wednesday, October 10, 2012 in Leiden, the Netherlands

*Laura van Hattum, secretary to the Eurotransplant International Board*

The Board was informed on the progress of the implementation of recommendations. First of all, the Board received an update regarding ESDP. The inclusion of patients has started. As soon as more centers actively participate in the study, it is expected that the inclusion of patients will speed up so that the study can be finished within a reasonable period of time.

During the meeting without the Directors, the President informed the Board about the work of the Directors since the extraordinary Board meeting in August. The Directors were separately called in to discuss their performance. Since the Medical Director had received an offer to become Medical Executive of the DSO, the Board asked him to stay. Rahmel informed the Board that he had decided to continue working for Eurotransplant.

The Board informed both Directors that an external audit of the organizational structure is planned

All centers have been asked to deliver LAS+ data to ET. The Dutch lung transplant centers together with the NTS are considering introducing LAS for lung allocation in the Netherlands. Until then, NTS is not in favor of collection the LAS data mandatorily. It was decided to ask the centers to enter the extended dataset for all recipients. In the case of the Netherlands data entry will not be made mandatory for listing.

The attendees were informed about the current status regarding plans to realize a pan-European Registry of National Registries for evaluation of organ transplants. This topic has also been discussed with representatives of the European Commission, that advised Eurotransplant to start cooperation with one or more larger organ allocation organizations with an interest with regard to evaluation of transplant results and organovigilance. Such cooperation would help give an EU funded sequel to EFRETOS a head start. For this reason, there has been contact between ET and ONT (Spain). ET met twice with ONT and the preparations for a sequel are on their way.

Next, Professor F. Perner, as special delegate of the Hungarian State Minister of Health, expressed the strong wish of Hungary to become a full member of ET. For a full cooperation the Hungarian laws need to be altered first. The

time which is left in 2012 is quite short and therefore it was not expected that Hungary would be ready for joining prior to the deadline of January 1, 2013. May 2013 was set as a realistic date for the start of full membership.

The report of the ET Liver Intestine Advisory Committee (ELIAC) was discussed. Since the report will be published in this issue of the ET Newsletter, there is no need to further elaborate on it in this summary.

The Board gave its approval for the ET budget for 2013.

The Board decided on a new mission statement for ET.

The definition of a resident was discussed by the Board in the context of the non-residents discussion in media and the wish to provide transparency as Eurotransplant to the general public and Authorities. The Board decided in a previous meeting on a transparency policy of non-residents transplantation and to publish the number of transplants of non-residents per center in the Annual Report. Since the different ET member states have different regulations on who is considered as a resident, it was decided to propose to the national authorities that ET will report the number of non-resident transplants in two ways: I. "nationals", that have been a "resident for more than 6 months" (regulations for Belgium, Croatia and Slovenia) and II. Those patients that are "residents more than 5 years" (European law). In the event ET's Competent Authorities achieve consensus on a common definition for resident, the publication in the Annual Report will be adapted accordingly.

Next, the Board was informed about the applications for the Henk Schippers Young Investigators (HSYI) Award 2012. The members of the HSYI Award committee unanimously declared Dr. Sebastiaan Heidt, Leiden, the Netherlands, as the winner of the 2012 HSYI Award.

Finally the Board discussed a joint action from the European Union regarding facilitating cooperation on organ donations between national authorities within the EU. Since no organization has the level of experience in the field of organ exchange as ET, ET was asked to participate in this project. The Board agreed that ET would take part in this project.

The following recommendations / policies have been discussed and approved by the Board:

**LIVER ADVISORY COMMITTEE****R-LAC02.12**

In view of the fact that the HU-status is not designed for patients with an acute on chronic decompensation, the ELIAC proposes to change the current criteria for eligibility for HU-status of patients with Budd-Chiari syndrome or Morbus Wilson from "rapidly progressive Budd-Chiari syndrome / Morbus Wilson" into;

"Acute liver failure due to rapidly progressive liver failure, caused by Budd-Chiari syndrome or Morbus Wilson"

Eurotransplant will monitor the effect of this recommendation by registration of the frequency of HU requests for these indications as well as the frequency of HU liver transplantation following these indications.

*This recommendation will be forwarded to the national authorities for authorization.*

**FINANCIAL COMMITTEE****P-FC02.12**

The Financial Committee recommends the Board to approve the budget proposal for 2013.

*This policy will be forwarded to the national authorities for information.*

**P-FC03.12**

The Financial Committee recommends the Board to approve the policy that all member states, including new member states, join in the "balancing of the reserves. Balancing of the reserves implies to charging or refunding the member states, depending on the state of the reserves.

*This policy will be forwarded to the national authorities for information.*

**THORACIC ADVISORY COMMITTEE**

*approved during Board meeting of May 14, 2012*

**P-ThAC01.12**

In order to be eligible for the e-LAS status patients registered in Austria, Belgium or the Netherlands should fulfill national HU criteria and be listed with a national HU status.

*This policy will be forwarded to the national authorities for information.*

**P-ThAC02.12**

Upon data entry for calculating the lung allocation score (LAS), the measurements should not be older than 4 weeks in case the calculated LAS is <50 and 7 days in case the LAS is ≥50.

*This policy will be forwarded to the national authorities for information.*



# Summary of the meeting of the Eurotransplant International Board on Wednesday, January 23, 2013 in Alpbach, Austria.

*Laura van Hattum, secretary to the Eurotransplant International Board*

The Board was informed on the progress of the implementation of recommendations. First of all, the Board received an update regarding ESDP. Since the last Board meeting only a few additional patients have been included into the trial due to less 0-DR-mismatch patients than expected on the one hand side and due to the fact that the number of participating centers and patients is still limited. It was decided to introduce different measures at the ET office in order to make centers more actively aware of possible candidates for inclusion.

The recommendations related to HLA typing and cross matching have resulted in a new draft version of the corresponding HLA guideline in Germany which has been discussed with the German HLA labs and the kidney experts.

Next, the Board was informed by the President of the results of the recent audit of the ET Directors. It was agreed to organize an extraordinary Board meeting to discuss different topics regarding the structure of the ET organization and management, the position of the Board and the Council.

The Director informed the Board on the EU Directive implementation. There are two areas which need to be implemented; vigilance and organ characterization. ET is, together with a working group of the ET Council, in the process of drafting an ET wide vigilance system which will further develop and standardize what is already in place within ET at this moment.

The Board was then informed on the progress of the sequel to the EFRETOS project. This is to be a large EU funded project which is expected to start no sooner than in 2014. The budget for this project will be decided upon in the summer of 2013. The Board was of the opinion that ET should at this moment focus on its own registry. The Directors will come up

with a plan on how to enhance the ET registry in the coming 2-3 years including the necessary resources, for the sequel of EFRETOS for the ET member states.

The Board received an update on the current situation in Germany.

The Board discussed the Hungarian membership application. The Hungarian law regarding possible organ exchange with other countries was changed December 2012 which cleared the way for a full membership. It is expected that the contract for a full membership will be signed before July 1, 2013.

Next, Dr Djukic, State Secretary for the Ministry of Health in Serbia, expressed the strong wish of Serbia to become a member of ET by organizing different twinning agreements to lay the basis for full membership of ET as soon as possible. The President and Directors were invited to visit Serbia in late spring/early summer to further discuss the possibilities for Serbia to become a member state.

The reports of the ET Liver Intestine Advisory Committee (ELIAC), ET Thoracic Advisory Committee (EThAC), ET Kidney Advisory Committee (ETKAC) and Organ Procurement Committee (OPC) were discussed. Since the reports will be published in this issue of the ET Newsletter, there is no need to further elaborate on it in this summary.

The Board gave its approval for the definite ET budget for 2013.

In the last Board meeting, the Board decided on a 0% policy of non-resident transplantation and publishing the number of transplants of non-residents per center in a transparent manner in the Annual Report. Since the different ET member states have different regulations on who is considered as a resident, it was decided to report the number of non-resident transplant in the following ways:

- “nationals”
- “resident for more than 6 months” (for Belgium, Croatia and Slovenia) and
- residents more than 5 years” (European law).

Also, a sentence will be added stating that children will have the residency of their parents.

From 2013, non-residents will be reported in the new way. The Board agreed to inform all centers and national authorities of this by letter and will publish a press release on the ET website.

The following recommendations and policies have been discussed and approved by the Board:



Eurotransplant Winter meeting

## Mark your calendar

**The Eurotransplant Winter Meeting 2014 will take place from January 22-24 in Alpbach, Austria.**



**LIVER ADVISORY COMMITTEE****R-LAC01.13**

In case of a donor procedure involving both the procurement of the small bowel and the pancreas, the procurement of the small bowel should be performed by a transplant surgeon experienced in intestine explantation. In addition the opportunity must be offered to the recipient (pancreas) center to send a surgeon to participate in the retrieval of the pancreas during the donor procedure.

*This recommendation will be forwarded to the national authorities for authorization.*

**THORACIC ADVISORY COMMITTEE****R-THAC01.13**

The first line rescue scheme for allocation donor hearts and lungs in ET will be performed according to the mini-match scheme. According to this scheme all centers in the same donor country (region for Germany) will receive a center offer. The center is asked to select one recipient from their waiting list. ET then allocates the organ to the patient with the highest position on the match list according to the general criteria.

*This recommendation will be forwarded to the national authorities for authorization.*

**P-THAC02.13**

The Total Lung Capacity (TLC) will be calculated as follows:

Donor 4-18 years\* height in cm

- Male donor <162.5 cm - TLC = ((-3.828)+(0.04976\*height))

- Male donor >162.5 cm - TLC = ((-10.648)+(0.09586\*height))

- Female donor - TLC = =SUM(-234.078+(7,03067\*height - (0,07802979\*(height^2)+(0,00038100528\* height^3)- (0,00000068597971\*height^4))

Donor >18 years\*\* height in meter

- Male donor - TLC = 7.99 x [height] - 7,08

- Female donor - TLC = 6,60 x [height] - 5,7

\*Rosenthal Thorax 1993; 48: 803-808

\*\*Zapletal et al. Standardization of lung function tests in pediatrics. The European Respiratory Journal 1989; 2, Suppl. 4. Ed. The Working Group Pediatrics SEPCR

*This recommendation will be forwarded to the national authorities for information.*

**KIDNEY ADVISORY COMMITTEE****R-KAC01.12 (rephrased)**

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. Upon registration on the waiting list the recipient will be granted a once-only allocation bonus of 500 points.

In exceptional cases, upon request of the transplant center, this bonus can be granted for a next transplant. Each request for a repeated bonus should be well motivated and will be evaluated by all ETKAC members.

*This recommendation will be forwarded to the national authorities for authorization.*

**ORGAN PROCUREMENT COMMITTEE****R-OPC02.11 (2nd rephrase)**

If a donor type is switched from being a potential non-heart-beating donor to a heart-beating donor Eurotransplant must restart the allocation process of organs that are not offered yet or become available for new offers.

*This policy will be forwarded to the national authorities for information.*

**P-FC01.13**

The Financial Committee recommends the Board to approve the definite budget for 2013.

*This policy will be forwarded to the national authorities for information.*

The following reports from the Advisory Committees were discussed by the Eurotransplant International Board on October 11, 2012 in Leiden, the Netherlands and January 23, 2013 in Alpbach, Austria

*Please note that all approved recommendations/policies mentioned in the following reports, are published elsewhere in this Newsletter.*

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

*Chairman: Prof.Dr. X. Rogiers  
Secretary: Joris Blok, MD*

*The ELIAC met on September 24, 2012*

*Members present: 9 + 1 Director + 2 ET co-workers*

*Members excused: 2*

### A. Liver registry project

The ELIAC is given an update on the Liver Registry project. There is no report regarding the Dutch centers, due to the fact that the Netherlands formally has its own registry (NOTR), to which the centers supply their data. ET uses the data collected in NOTR only with formal consent of the NOTR. It is suggested that tier 0 data (patient and graft survival, cause of death and date last seen) shall be automatically integrated into ENIS. ET will contact NTS with this request. NOTR does have a contract with ELTR, to which the follow-up data of the three centers is sent.

German transplant centers are required by law to upload their data to the "AQUA" institute. ET cannot deliver the data to AQUA on behalf of the centers for legal reasons. Currently ET is working on a plan where the data that the centers are obliged to send to AQUA is also sent to ET.

### B. Cooperation with ELTR

The cooperation with ELTR was discussed. The question arose if there is need for a new contract with ELTR or ELITA. There is need for more clarity regarding the legal responsibility. The issue of auditing the centers is addressed also. Currently the ELTR organizes audits of the centers, but they have asked ET to assist with these audits financially. Since ET and the ELIAC are interested in complete and accurate data, it might be an option to combine ET data audits of the centers with the ones performed by ELTR. An auditing team of one ELTR auditor, one ELIAC auditor and Vincent Karam could be created in case an ET center has to be audited. This would be a win-win situation because efforts of both organizations could be combined and the costs for both organizations thereby reduced. This issue has to be discussed in the Board, whether the auditing is part of the ET aims.

The ELIAC agreed to create a new contract between ELTR and ET in which data safety, data exchange and the proposed auditing system is laid down.

### C. Developments in liver allocation

#### *Current situation in Germany*

The current knowledge regarding possible manipulation of data entered into ENIS by German centers thereby influencing the MELD-Score of individual patients is presented.

The key question remains how to detect and if possible prevent this problem in the future.

In Germany a framework action plan has been developed. There is some discussion on how to practically implement this plan. The laboratory physicians have made their own proposal that is supposed to increase reliability of the lab data provided to ET.

It was decided to introduce onsite audits in the transplant centers. Furthermore, the insurance companies have advised against the policies of rewarding a bonus per transplant. Issues that are still sensitive are rescue allocation. ET will think about measures to support national responsible bodies in controlling data and achieving high data correctness.

A more general issue that is addressed in this context is the continuous improvement of the liver allocation system. Modifying the system so that not only urgency but also outcome of the transplantation is taken into account has been discussed earlier several times. This is why the collection of follow-up data is so important. Furthermore an adjustment in the rescue allocation policy might be helpful to increase the transparency of the system. A proposal to achieve that could be a system using MELD in a sort of 'mini-match'.

#### *Eurotransplant and data control*

Regarding data control and support for the national responsible bodies for the control of the centers, the ELIAC members are asked to think about which data should be looked at by ET and what function ET should have in this matter. Two major aspects have to be distinguished: a) refinement of the plausibility checks at the time of data entry. b) statistical analysis of the data to detect conspicuous features. The ELIAC members are asked to support the ET office in developing respective standard procedures.

### D. Presentation study results

#### *Presentation results ELIAC study by A.E. Braat*

Dries Braat, transplant surgeon at the LUMC, informed the ELIAC on the results of the study "Predictive model for liver graft failure after liver transplantation: research of the Eurotransplant database". There are two articles already published and one submitted. The ELIAC members support the newly presented study proposals.

It is asked how the investigators want to practically use the ET-DRI in the allocation. It would not be possible to calculate the ET-DRI beforehand on the donor report, since some factors are allocation related. An option would be to calculate the ET-DRI on the match report for individual recipients.

It is proposed for the validation study of the ET-DRI to calculate the ET-DRI with and without the factor 'rescue allocation'. Rescue allocation actually represents the 'expert opinion' of the ET community (three medical declines). It will be important to see if the ET-DRI has a sufficient predictive capacity without this "expert opinion factor". Another option could be to recalculate the ET-DRI in case an organ is declined 3 or more times due to medical reasons. This new ET\_DRI could then be used in further allocation. This might even help in objectifying when to really start rescue allocation.

*Presentation study proposal ELIAC study by M. Coenraad*  
Minneke Coenraad, hepatologist at the LUMC, presents a study proposal on liver transplantation for HCC within Eurotransplant. The ELIAC is informed that ET will facilitate this study by approaching the centers with a letter and dataset to be filled out. In order to make it as easy as possible for the centers, ET will already fill out as many information as possible. There is currently a similar study in Belgium on this topic. It is decided that the centers will first be contacted if they want to collaborate with the study after which the eCRF's will be forwarded to them. The ELIAC supported the study proposal.

### E. Consequences of new allocation sequence pancreas-after-intestine

The ELIAC concluded that it will be difficult to change the current rule, since the current rule is considered important to give a realistic chance for intestine recipients. All cases of intestine procurement without pancreas transplantation will be discussed with the EPAC.

## Report of the meeting of the Eurotransplant Financial Committee (FC)

*Chairman: Prof.Dr. A. van Montfort*  
*Secretary: Drs. T. Valkering*

*The FC met on September 26, 2012*  
*Members present: 4 + 1 Director*  
*Members excused: 2*

### A. Eurotransplant financial report January-July 2012

The financial report over the period January-July forecasted a positive result over the year 2012 (for these six months almost 250 k€), while a negative result was expected in the budget proposal 2012. The most important contribution to the result came from the delay in the LAS project. Expenditures on the project and on additional work to compen-

sate for time spent on LAS in 2011 were lagging behind the expectations at the end of 2011. Also hardly any expenses were made on the projects "disentanglement of shared services" and "information security". Savings were realized on staff expenses, due to vacancies. Since these vacancies also concerned some key positions (team leader IT development, enterprise architect, business analyst) and since a lot of attention went to the housing project, the projects were behind schedule.

### B. Eurotransplant budget proposal 2013

The budget proposal 2013 was accompanied by an explaining memo "Plan and Budget 2013", in which the developments which ET was facing were elucidated and translated into activities in 2013 and on. These activities were financially translated and represented in the budget proposal 2013. On the whole a deficit in exploitation of 300 k€ is forecasted for 2013.

The FC chairman raised the question on the plausibility of the forecast. Since the estimated result for 2012 differed rather significantly from the forecasted result, this should not be the same in 2013. The foreseen strategic activities mentioned in the memo "Plan and Budget 2013" imply additional expenses, although not budgeted for, and since the responsible staff is at full strength again, the plausibility of realization of plans is higher than in 2012. Therefore the forecasted budget was considered to be credible and thus realistic.

There was a discussion on the balancing of the reserve. Balancing of the reserve might have a positive or a negative effect on the contribution of member states and in both cases all member states are charged or will benefit. For this reason it was decided that, in case settlement means refunding, the refunding will be of benefit to all member states, including Hungary as a new member.

## Report of the meeting of the Eurotransplant Pancreas Advisory Committee (EPAC)

*Chairman: Prof. Dr. W. Schareck*  
*Secretary: M. van Rosmalen, MD*

*The EPAC met on Thursday, October 11, 2012*  
*Members present: 12 + 1 director + 3 ET co-workers*

### A. Progress on renewed data exchange with IPTR

The revised agreement between IPTR and ET for the exchange of pancreas follow-up data has been approved and signed by all parties and sent to all ET pancreas transplant centers for approval. 39% of the consent forms have been signed by the ET pancreas transplant centers so far. It is intended to start data exchange between ET pancreas centers and IPTR by January 2013. The centers do not have to double register the recipient follow-up and can request data from the IPTR.



## B. Pancreas follow-up registry

In this stage the elementary data of *transplant survival*, *patient survival* and *date last seen* are collected. In a later stage other relevant at this moment still missing data will be collected. Currently 64% of the elementary data is collected. A short summary is given in the booklet prepared for the pancreas users meeting.

## C. Discussion on kidney-after-pancreas transplantation (RKAC03.11)

The EPAC proposal for granting bonus points for kidney-after-pancreas transplantation derived from the equal kidney-after-liver recommendation was discussed during the last ETKAC meeting and resulted in a similar recommendation for kidney-after-pancreas.

The recommendation was formulated based on an offer of a good quality pancreas without an accompanying kidney, to prevent pancreas loss due to non-acceptance (for example in case the kidney is allocated with heart and liver or kidneys in poor condition).

During the present EPAC meeting the EPAC members stated that the situation of transplanting kidney-after-liver is not comparable to kidney-after-pancreas, because simultaneous kidney and pancreas transplantation is preferred in recipients with a poor clinical condition. Therefore the recommendation might not be completely appropriate for this category of patients.

It was decided to further analyze the possible benefit of pancreas-only acceptance in order to prevent the loss of single pancreata as well as to analyze the possible benefit of pancreas+kidney transplantation with a pre-emptive state of renal failure. Dependent on the results of these analyses new recommendations will have to be formulated.

## D. Quality of pancreas procurement

The current implementation of and developments regarding procurement guidelines for German pancreas procurement surgeons were presented.

The following selection criteria for becoming a pancreas procurement surgeon in Germany are intended to be implemented:

- being abdominal surgeon working in a transplant center;
- participation in Walter-Brendel-Kolleg for transplant medicine (recommended);
- completion of a TOP-course (recommended);
- having performed 25 autonomic multi organ procurements (independent of the outcome);
- having performed 5 autonomic pancreas procurements under surveillance;
- having assisted at 5 pancreas transplantations as 1<sup>st</sup> assistant.

These conditions have to be verified by operation reports or procurement protocols.

It was explained that Dutch pancreas procurement surgeons have to take part in a TOP-course and an E-learning module on anatomy and pitfalls of pancreas procurement (Baranski course). Pancreas procuring surgeons must perform 10 pancreas procurements under guidance and 5 complete abdominal procedures.

The Austrian EPAC representative informed that in Austria implanting surgeons are also involved in the procurement of the pancreas.

In relation to above mentioned guidelines in the framework of education of pancreas procurement surgeons, it was advised to not only look at the numbers of procured pancreata but also at the quality of procured pancreata by making use of quality forms.

It was agreed upon to continue the discussion on pancreas procurement through the community platform ETandI which should result in the formulation of a general recommendation about pancreas procurement.

## E. Consequences of the new allocation sequence pancreas-after-intestine

The topic of the loss of pancreata possibly due to intestine procurement remains a delicate topic for the members of the EPAC. The ELIAC had analyzed some cases and concluded that only in one of the cases the new allocation rule might have caused loss of the pancreas graft and for this reason the ELIAC had stated not to be in favor of reversal of the allocation sequence.

The EPAC agreed upon to organize a joint EPAC-ELIAC meeting in order to come to a solution.

## F. Progress on study ‘determining genetic factors that can predict the loss of transplanted pancreas function’

The study initiated by the Oxford University in the UK had been discussed in the ET Ethics Committee (ETEC) which resulted in some comments on legal aspects and the aim of the study.

After the representative from the Oxford University, who was present at the EPAC meeting, had explained the comments involved, the EPAC voted in favor of the study.

## G. Establishment of program for immunized pancreas recipients

The EPAC discussed the establishment of a program for immunized pancreas recipients. The German representative proposed the option for an immunized program which concerns to qualify the recipient for the AM program after 5

pancreas offers having been declined due to proven immunological incompatibility in each of these offers. The EPAC is not in favor of this proposal.

It was stated that if no donor HLA is known at time of the offer, the pancreas should be allocated to non-immunized recipients only. Otherwise the risk of a positive cross match in highly immunized recipients would be high, jeopardizing the final acceptance. The EPAC agrees.

The Austrian representative mentioned that the HLA donor typing is more difficult in small hospitals. A possible solution is to postpone donor reporting to ET until the donor HLA typing is known (taking the minimal allocation time into consideration).

It was proposed to prioritize all immunized recipients over all non-immunized recipients, maintaining the SU tier. The allocation sequence would be as follows:

- SU immunized recipients (international, ranked on waiting time), then
- T immunized recipients (national before international, ranked on waiting time), then
- SU non-immunized recipients (international, ranked on waiting time), then
- T non-immunized recipients (national before international, ranked on waiting time).

This option implies a change in the allocation sequence from national before international to immunized before non-immunized. The EPAC agreed upon this option.

The question remained what to do with recipients participating in the AM program (having had a PRA value of  $\geq 85\%$  in at least two different samples) with a low current PRA%. These recipients will be downgraded in the ranking according to their current PRA%. This subject should possibly be addressed to the TTAC.

It is concluded that this topic needs further discussion, which will be continued on the community platform ETandI and during the upcoming EPAC meeting.

## Report of the meeting of the Eurotransplant Organ Procurement Committee (OPC)

*Chairman: Prof. Dr. D. Ysebaert*

*Secretary: Dr. I. Tieken*

*The OPC met on Monday, December 3, 2012*

*Members present: 13 + 3 observers + 1 directors + 1 ET co-worker*

*Members excused: 2 + 3 observers + 1 ET co-worker*

### A. Progress report on implementation of recommendations

The already approved recommendation R-OPC02.11 (rephrased) was again topic of discussion due to the fact that one Board member had suggested to delete a part of this recommendation as this specific part might be prone to manipulation.

The majority of OPC members did not share the concern for manipulation and based on an explanation by the ET medical director, the OPC accepted that the allocation should only be restarted if organs are not offered yet or become available for new offers. Despite the fact that the fear for manipulation is small, not only whether centers change the donor type but also their number of changes will be monitored. In the event of suspicion of manipulation by a specific center the national authority will be informed about this.

### B. Discussion on improvement of reporting of donor match criteria

The OPC discussed the following proposal by the ET office:

1. In all donors, with the exception of those mentioned at point 3, the items mentioned in point 5 are mandatory and need to be entered in the national donor application system before the donor can be reported to ET.
2. For all mandatory items (point 5) only “yes / no evidence” can be entered.
3. In case where the collection of complete data is not possible or might result in the loss of the donor organ, the donor can be reported as a donor qualified as a ‘donor with incomplete data’. In such cases it is not necessary to provide all mandatory fields mentioned in point 5.
4. Transplant centers should carefully consider the risk versus benefit for their recipient before accepting the organ offer of a “donor with incomplete data”.
5. Mandatory items: Malignancy, IV drug abuse, sepsis, meningitis.

It was commented that the items “malignancy, IV drug abuse, sepsis, meningitis” must be known prior to donor reporting. This information is important for the match and for the transplant centers to decide on the organ offers. Another comment was that the EU directive includes also the serology of HBV, HCV and HIV. If these items should also be included in the before mentioned options, this could lead to delay of the allocation procedure and might eventually lead to loss of organs.

Next it was proposed to have two levels in reporting donor match criteria:

1. The first level with mandatory data (malignancy, IV drug abuse, sepsis, meningitis);  
The donor can only be reported if these items are entered.
2. The second level being mandatory but not always directly available (e.g. serology) prior to reporting the donor.

Waiting with reporting the donor and offering the organs might lead to an undesirable delay of the allocation or even loss of organs. Therefore organs should be allocated according to the recommendation that was proposed.

The OPC finally agreed that ET will make a new proposal in which the two levels are mentioned. The new proposal will be discussed at the next OPC meeting.

The Austrian OPC representative asked whether in other ET countries there exists a possibility to perform a frozen section in every donor procedure because of any unexpected

findings (e.g. suspicion of malignancy) in order to prevent organ loss or high risk transplants. All other countries do have the capacity of 24/7 research by a pathology department, but sometimes it is necessary to send the frozen sections to one of the transplant centers. Austria will try to also have 24/7 research capacity by a pathology department.

### C. Donor data improvements

With regard to the time limits in donor lab values coming available in the course of a donor procedure, it was decided to perform an analysis on:

- how often are donors reported with lab values, X- ray etc. that are more than 24 hours old or missing;
- how often updates are asked;
- how often it is not possible to give an update.

Based on the results of this analysis a policy on the time limits of donor lab values will be made.

With regard to reporting of the medical history of donors it was addressed that too many yes/no fields might lead to oversee important points.

The OPC members decided that the current comment field will be divided in four comment fields:

- current medical findings – anamnesis;
- medical history;
- logistics;
- other comments.

### D. Quality forms

With regard to the planned development of a web based quality form registration application, the OPC members were presented with a presentation of a demo version of the Dutch quality forms application and were asked to comment on this application.

The OPC members agreed upon that preferably one web based registration system should be used for the evaluation of the procurement. The Dutch and German representatives commented that they prefer their own system. Both are willing to cooperate in order to detect differences and how these can be harmonized.

The conclusion of the discussion was that a working group should be formed. This group should look at the data set of both systems and try to overcome the differences between the systems. The differences should be discussed in order to develop one uniform web based registration system or at least make exchange of data feasible.

This working group should keep in mind that they first make a protocol in which the following questions are answered before discussing the development of the system:

1. For which purpose will the application be used and for whom (e.g. procurement surgeon national authority)?
2. Which information is therefore required?
3. What kind of communication between transplant center and donor center is required? etc.

The OPC furthermore agreed upon that email will be the most appropriate way to organize the communication between procurement and transplant surgeons. The direct contact between procurement and transplant surgeon is necessary for the education of procurement surgeons and eventually the improvement of the procurement. Keeping the list of email addresses up-to-date will be the responsibility of the competent national authorities.

### E. Improvement of procurement

The German EPAC representative presented the OPC members with the results of the work that has been done in order to develop criteria for surgeons in Germany to be certified for the procurement of abdominal organs. These criteria are proposed in order to improve the procurement of abdominal organs especially the procurement of the pancreas. For all organs a minimal number of procurements as trainee as well as as responsible surgeon is required. For the pancreas the surgeons have to fulfill some extra criteria. The expectation is that these new criteria for procurement surgeons will be implemented and published in the 'Richtlinien' by the beginning of 2013.

Besides Germany, only in the Netherlands there exists a specific training program for procurement surgeons.

The OPC members were concerned about the number of procurements Germany requires for surgeons to become a procurement surgeon; especially for the pancreas the numbers are high which might lead to a very long training period or eventually to a very small group of surgeons that are certified to perform the procurement.

### F. Requirements on identification of procurement teams

To determine an appropriate future procedure within ET, the ET Council requires information from the OPC members regarding the current national regulations and legislation regarding the identification and qualification of procurement teams.

At the beginning of the discussion some of the OPC members seriously questioned the need for such an identification and qualification of procurement teams. For over 40 years this was not necessary and there had never been a problem. This is bureaucracy and will in the end lead to more paper work.

The discussion resulted in the following conclusion:

- In order to prevent a bureaucratic solution the OPC members agreed that a list of accredited procurement surgeons should be made available by the national competent authorities and that this should be accessible to all persons involved in a certain donor procedure.
- If a surgeon is crossing the border only identification should be required. With the identification the surgeon can be found in the list of accredited procurement surgeons.
- The topic should be placed on the agenda of the EThAC.

In almost all cases only thoracic surgeons are crossing the borders to procure an organ. Therefore the EThAC members will be asked whether they agree with the proposed procedure.

With regard to the current stern demands by the Hungarian authorities regarding identification of foreign procurement teams, it was agreed upon to ask the Hungarian authorities to consider adopting the proposed solution.

### G. Risk assessment for logistical chain for donor organs, procurement teams and cross match material

In the context of the accession process of Hungary, the OPC members were presented with the differences and similarities between the countries of which ET received a questionnaire for assessing certain logistical risks within the ET region and Hungary. ET will wait until all countries returned the questionnaire in order to compose an advice to the Board with regard to the management of risks in the logistical chain for donor organs, procurement teams and cross match material for ET.

### H. Proposal for logistic guidelines regarding shipping documents

After a short discussion the OPC members agreed upon the following policy:

Both shipping and medical documents should be placed in separate areas of the transport box: the shipping documents *on* the outside and the medical documents preferably *in* the transport box (e.g. the area for XM material in the cover of the transport box).

## Report of the meeting of the Eurotransplant Thoracic Advisory Committee (EThAC)

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

*The EThAC met on Wednesday, December 12, 2012*  
*Members present: 12 + 1 external advisor + 1 director*  
*+ 1 ET co-worker*  
*Members excused: 3*

### A. Announcements

The new German EThAC member, Dr. Ingo Kaczmarek from Munich was welcomed and introduced as well as the Hungarian observer, Dr. Zoltan Szabolcs. The EThAC meeting was attended by an external advisor from the lung transplant program Groningen, the Netherlands who plead for the introduction of a TLC calculation for pediatric lung patients.

### B. Progress report on the Lung Allocation Score (LAS)

The EThAC members were informed about the results of LAS since the implementation in December 2011. The EThAC concluded that LAS works rather satisfying and that all trends are positive.

In Germany it is observed that the higher the LAS the more likely patients are transplanted. This occurs despite the fact that 30% of all lung transplants are performed via rescue allocation. This trend results in the fact that patients with lower LAS are systematically selected in the rescue allocation.

In order to prevent this undesired trend the EThAC formulated R-ThAC01.13 which stands for a mini-match scheme.

The EThAC furthermore discussed some practical issues that are still to be resolved. To this end a meeting will be scheduled for the members of the LAS Review Board.

The EThAC was informed that due to the current German situation with regard to manipulation of data, ET is in the process of extending and refining plausibility checks for organ data entries.

### C. Pediatric donor TLC

ET had received a complaint from a pediatric pulmonologist at the University Medical Center Groningen, the Netherlands that the current TLC calculation for pediatric donors is not appropriate. He claimed that the current ET TLC calculation is based on a – mainly – adult reference population which is used for all donors (adult as well as pediatric). The EThAC members supported his suggestion to implement a TLC calculation for pediatric donors and formulated P-ThAC02.13.

### D. Report of the Cardiac Allocation Score (CAS) project

The aim of this project would be to allow heart transplant clinicians to become familiar with the CAS and to gather information to further improve the model. There is at present no intention to change to heart allocation from an HU system to a CAS system.

Similar as with the LAS, ET will make the CAS application available for all ET countries via the registration cascade.

ET has drafted a technical guide that explains in detail how the CAS is constructed.



## Report of the meeting of the Eurotransplant Kidney Advisory Committee (ETKAC)

Chairman: Prof. Dr. U. Heemann

Secretary: Dr. J. de Boer

The ETKAC met on Wednesday, December 19, 2012

Members present: 16 + 1 external advisor + 1 director

Members excused: 2

### A. Adaptation of the kidney allocation system

In a joint meeting with the ET Tissue Typing Advisory Committee (TTAC), the ETKAC discussed the adaptation of the current kidney allocation system.

Two previously approved recommendations serve as a basis for the discussion:

- The selection of recipients will be according to RKAC02.08;
- The donor categories will be in accordance with RKAC04.11.

#### RKAC02.08

Kidneys should be allocated to ABO identical recipients. Exception should be made for:

- The acceptable Mismatch (AM) program: kidneys should be allocated to ABO compatible recipients;
- Combined organ recipients: kidneys should be allocated according to the ABO blood group rule of the leading organ;
- Rescue allocation: selection of recipients should preferably be ABO identical.

#### RKAC04.11

Kidneys from deceased donors are classified according to the following criteria:

- donor age, kidney function and co-morbidities;
- category 1: donor age <16 years;
- category 2: donor age 16 – 49 years;
- category 3: donor age 50 – 64 years;
- category 4: donor age ≥65 years;
- category 5: special donor category for poor quality organs.

Donors from the categories 2 and 3 who at least meet two of the following criteria will be categorized into the next higher category:

- creatinine prior to donation is >1,5 mg/dl;
- the cause of death is cerebrovascular and the donor has a history of hypertension;
- the donor suffers from diabetes mellitus.

All donor categories are allocated according to the following principle with two exceptions

*Ranking of allocation:*

- AM program;
- Full-house recipients;

- Special priority recipients
- HLA-DR+;
- HLA-DR;
- 1 HLA-DR mismatch.

These exceptions are:

- Donors <16 years of age (Category 1). Organs from these donors are, within each tier, offered primarily to children.
- Organs of category 4 – with a donor age of ≥ 65 years – are initially allocated according to the current ES(D) P scheme and thereafter the proposed scheme above will be followed with exception of the DR+ (Tier 4) allocation.

*HLA DR allocation:*

All kidney grafts should preferably be allocated with a full match for HLA-DR.

*HLA-DR+ allocation:*

Recipients who are likely to receive a consecutive graft should be allocated a graft which is additionally matched for at least 2 loci on HLA-A and/or HLA-B.

*1 HLA-DR mismatch:*

Organs from donors with rare HLA DR antigens will be allocated with 1 DR mismatch in the event no full DR matched recipients are available.

*Geographical considerations:*

In order to minimize ischemia times and unnecessary shipping, within each tier, organs will be distributed, if possible, within the same region or country. Second the allocation will be according to geographical clusters:

1. Belgium, Luxembourg and the Netherlands
2. Germany
3. Austria, Croatia and Slovenia (in the future including Hungary)

*Balancing Principle:*

If an organ is not transplanted in the country of origin (A) but in another ET country (B), recipients on the waiting list in the country of origin (A) are prioritized within each tier, in case a donor is available in the country of transplantation (B) until an organ of the country of transplantation has been returned to the country of origin.

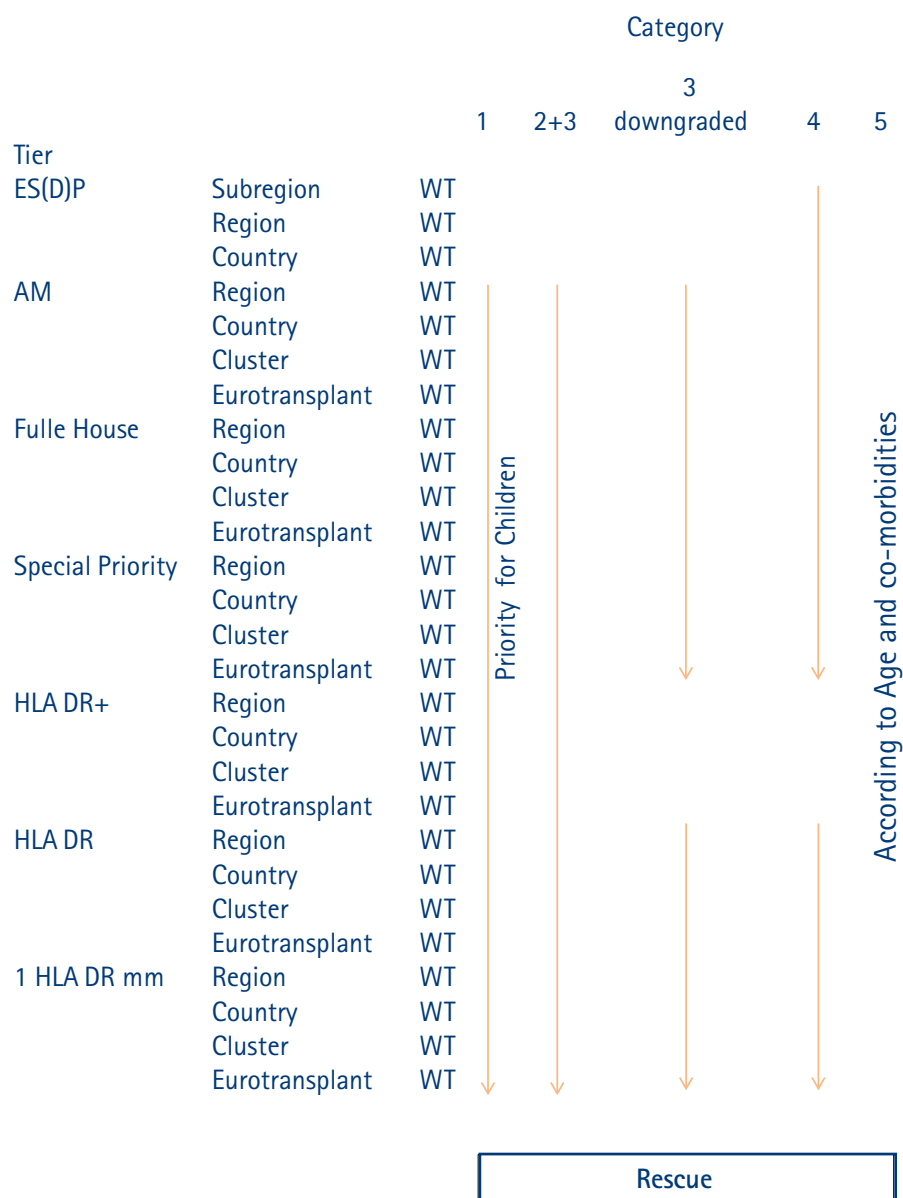
If the country of transplantation (B) has already transferred an organ to a third country (C), recipients of country A are also treated as recipients of the country C and so forth.

This rule applies for organs of the same donor category and blood group.

*Waiting time:*

If, within one cluster, more than one recipient is identified, the organs will be allocated according to the relative waiting time. In order to avoid disadvantage for recipients from countries with relatively short waiting times waiting time is adapted for the differences between the countries.

This would result in the following scheme:



Further details will be worked out during the next ETKAC meeting.

**B. Dutch comment on RKAC01.12**

R-KAC01.12

*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. Upon registration on the waiting list the recipient will be granted a once-only allocation bonus of 500 points.*

*In exceptional cases, upon request of the transplant center, this bonus can be granted a second time. Each request for a repeated bonus should be well motivated and will be evaluated by all ETKAC members.*

The ETKAC discussed a comment by the Dutch Transplant Foundation (NTS) that concerned the risk that centers might take the opportunity to apply for a double bonus. In order to avoid misunderstandings the ETKAC formulated R-KAC01.12 (rephrased).

**C. Code of Conduct for kidney audits**

The ETKAC approved the final version of the Code of Conduct and agreed upon implementation by 1 January 2013.

**D. Follow-up on a joint ETKAC/OPC meeting on machine perfusion**

Following the discussion at the joint ETKAC/OPC meeting the machine perfusion study group developed a new study: “Center oriented Hypothermic Machine Perfusion after Static Storage (Compass)”.

This study focuses on ECD donors, putting the kidney after arrival at the transplant center either on the perfusion machine or keep the kidney in the cold storage until transplantation, according to a randomized scheme.

ET is only involved in the data collection.

The ETKAC accepts the study proposal under provision that potential reallocation of the kidney (f.i. in case the regional HLA cross match turns out to be positive) is not hampered.

## E. Data exchange with the CERTAIN registry

In the framework of the ET Registry policy plan data exchange with the Cooperative European Pediatric Renal Transplant Initiative (CERTAIN) registry was initiated. The exchange works satisfactorily. The ETKAC was informed that the data exchange works satisfactorily.

## F. Data exchange in the framework of the RichQ study

ET was requested to deliver transplant follow-up data including general donor- and recipient data and pre-transplant immunological data for the RichQ study initiated by the Rotterdam pediatric transplant center in cooperation with some other pediatric transplant centers. The “Renal Insufficiency Therapy in Children: Quality Assessment and Improvement (RichQ)” aims to improve quality of treatment of children with chronic renal replacement therapy by setting up protocols and guidelines. The ETKAC approved the proposed data exchange.

## G. Non-heart-beating (NHB) type II donor allocation in Belgium

The ETKAC was informed that the Belgian Kidney and Pancreas committee (KPC) formulated a proposal to allocate NHB type II kidneys (according to Maastricht protocol) as a center offer in Belgium. The ETKAC had no objection to this proposal, provided that a formal statement of the Belgian transplant community, authorized by the Belgian competent authorities supporting this proposal is submitted to ET.

# Report of the meeting of the Eurotransplant Tissue Typing Advisory Committee (TTAC)

Chairman: Prof. Dr. F. Claas

Secretary: Prof. Dr. I. Doxiadis

The TTAC met on Wednesday, December 19, 2012

Members present: 9 + 1 observer

Members excused: none

## A. Announcements

The new Austrian TTAC representative, Prof. Gottfried Fischer was welcomed. It was announced that the TTAC secretary and ETRL managing director, Prof. Ilias Doxiadis, will retire in the course of this year. It was furthermore announced that the report of External Proficiency Testing (EPT) data will be done electronically in the future.

The German TTAC representatives informed that in Germany it is planned to stop sending out sera for sensitized patients. A recommendation will be formulated in due time and after acceptance of all ET countries this will be implemented.

## B. Automatic input of histocompatibility data

All ET affiliated Tissue Typing Centers have been informed by mail about the possibility of automatic input of histocompatibility data and the respective link has been passed. The TTAC strongly advised that for any changes/new items involving transplantation immunology the TTAC should be informed and that the final control should be done by the ETRL. The members of the TTAC are satisfied with the possibility of entering the results electronically and ask whether unacceptable HLA antigens can be entered in a similar way.

## C. Screening for HLA specific antibodies of kidney, pancreas, heart and lung patients

With regard to the liver transplant recipients the ELIAC will receive additional information from the current literature.

## D. New allocation parameters

The TTAC discussed the points of the joint ETKAC/TTAC meeting that took place earlier that day. There are some explanations needed with respect to matching. Until now ET based the allocation on *mismatching* while from now on more emphasis will be given to matching. In this respect the following scheme is important:

Donor	Patient	Matching	Mismatching
HLA-A2, A2	HLA-A1,A2	1	0
HLA-A1, A2	HLA-A1, A2	2	0
HLA-A2, A2	HLA-A2, A2	2	0

*The same holds true for HLA-DR.*

This way homozygous patients will primarily be offered organs of homozygous donors. In case no homozygous patients are present then the organs can be allocated to heterozygous patients.

### *Acceptable Mismatch program*

Patients will be accepted on the waiting list for the prioritized program on the basis of the chance to be offered a suitable cross match negative organ.

The TTAC discussed to propose to the ETKAC a recommendation that a patient can only enter one priority program like AM. In this case the patient will not be offered organs from ETKAS.

The % virtual PRA value will be based on the HLA antigens listed as unacceptable for the patient.

### *New allocation parameters*

As a result of the ETKAC/TTAC meeting the TTAC will propose that no cross match sera should be sent around and that no prospective cross match for unsensitized patients should be done.

met on Wednesday, May 23, 2012 at the Eurotransplant office at which occasion the following issues were discussed.

## A. Information Policy: Enterprise Architecture

Enterprise architecture helps an organization figure out how to best execute the strategies that drives its development. It is the organizing logic for business processes and IT infrastructure reflecting a comprehensive operating model of the organization. The operating model is the desired state of business process integration and business process standardization for delivering services to customers.

Enterprise Architecture (EA) is used to integrate in one picture a scattered landscape of strategies, processes, applications and their relationships. If we for instance decide to make adaptations to the ENIS system, having such an EA picture will facilitate making an inventory of all involved processes and create an insight of the effects on both business and IT. End users will not notice much of the enterprise architecture itself as it is a tool to organize strategy into projects and processes within the organization. It is important to balance between investing too much and too little time and effort in this set of tools.

## B. Information Security

Information security is a topic of increasing importance and an ET Information Security policy is necessary to be accountable in regard to the confidentiality, availability and integrity of information that ET processes and stores in its data bases. Information security is not mainly an issue for IT, but also for the business. ET will work towards meeting the requirements of the international ISO-27001 standard for information security.

## C. Program and project management

The communication before, during and after a project is crucial to monitor progress, identify problems and take corrective measures. In order to be effective in project management the Information Services (IS) department tries to understand how decisions are made with regard to occurring problems, delays or the interference of projects with higher priority. Also communication between business and IT is very important and has increasing attention of the IS department. The better the communication is, the more successful a project is.

## D. Community Concept (ET&I)

An update on the plans and developments was presented. The pilot with a group of innovators started by the beginning of June 2012 and the first results have been presented at the annual ET meeting, October 2012. ET should develop a plan on how to bring the topic to the attention of the community. It was suggested to introduce topics that attract people,

although ET should not be the body to introduce topics. The community itself has to introduce topics and start discussions on ET&I.

## E. Registry

The EFRETOS data sets for all organs become more and more leading in the ET follow-up registry. The ISWG is of the opinion that the tier-1 set should be standard for the follow-up of all organs.

The ISWG members agreed upon that multi-lingual service of the registry towards the centers is practical and helps to increase cooperation and high data completeness.

It was inquired after ET's possibilities to perform co-variate analysis on the follow-up data, so that a country can compare itself with the ET area. It was explained that a request for a specific analysis by ET is possible. It depends on the topic whether an organ Advisory Committee has to agree on the suggested analysis or not. Also the fact must be taken into account that ET does not always have complete follow-up data on variables other than outcome data for which reason analysis is not always possible.

There was a question about the status of the file upload possibilities for registry data. It was explained that the registry department is currently working on a simple solution with one prescribed file and data format, but that in the future, when a working registry for all organs is in place, a web service for more flexible data transfer will be developed.

There was a suggestion of further developing the idea of an audit system where centers audit other centers on the quality and completeness of their registry data. All agree that this topic would be interesting to discuss on a forum of ET&I.





# Eurotransplant

## new mission statement

Organ transplantation offers life-saving and quality-of-life enhancing treatment options to patients with end-stage organ failure. Aiming to fulfill this potential, Eurotransplant was established and acts as a mediator between donor hospitals and transplant centers, for the benefit of such patients.

Eurotransplant is a non-profit, international organization that facilitates patient-oriented allocation and cross-border exchange of deceased donor organs at the service of its member states.

As such,

- Eurotransplant manages the complex process of achieving the best possible match between available donor organs and patients on the transplant waiting list.
- Eurotransplant acts transparently and in accordance with European Union regulations and ethical principles, and fully complies with national member state legislation.
- Eurotransplant is actively engaged in developing best practice recommendations and policies to further improve organ allocation and transplant outcomes, based on robust data collection and state-of-the-art scientific research.

## Report of the Eurotransplant Assembly on October 11, 2012 in Corpus Congress Center, Leiden, the Netherlands

*Chairman: Prof.Dr. Günther Laufer*

*Secretary: Verena Diepeveen*

*The meeting is attended by 240 participants.*

### Opening

The chairman opens the meeting and welcomes all participants.

### Re-election of three Board members A

#### *Kidney section*

According to the Eurotransplant Articles of Association, the current Board member A in the kidney section, Prof. Uwe Heemann from Munich (GMHTP) has to be (re)-elected. Since no other candidates applied for this position and Prof. Heemann had declared to be available for another term, he is re-elected by the Assembly as a Board member A in the kidney section.

#### *Thoracic section*

According to the Eurotransplant Articles of Association, the current Board member A in the thoracic section, Prof. Günther Laufer from Vienna has to be (re)-elected. Since no other candidates applied for this position and Prof. Laufer had declared to be available for another term, he is re-elected by the Assembly as a Board member A in the thoracic section.

#### *Tissue typing section*

According to the Eurotransplant Articles of Association, the current Board member A in the tissue typing section, Prof. Caner Süsal from Heidelberg has to be (re)-elected. Since no other candidates applied for this position and Prof. Süsal had declared to be available for another term, he is re-elected by the Assembly as a Board member A in the tissue typing section.

The three members re-elected are congratulated with their appointments as members A in the Eurotransplant International Board.

### Announcement of the winner of the Henk Schippers Young Investigators award

Henk Schippers became the first Eurotransplant Director in 1970. After 5 years, he was appointed secretary/treasurer of the Board until his death in 2003. Henk laid the foundations for the administration of Eurotransplant. He successfully completed negotiations with the insurance companies and initiated the international network, which is now a hallmark of Eurotransplant. To commemorate his pioneering work for Eurotransplant a young investigator award in his name was established in 2003.

The purpose of this award is to encourage young clinical and/or scientific investigators to pursue a career in the field of organ and tissue transplantation. The Henk Schippers Young Investigator Award – consisting of an amount of



€ 2.500,00 and a certificate – is especially meant to enable the investigator to present his/her results of clinical and/or scientific organ transplantation related investigations at well recognized and respected international transplantation congresses or symposia, e.g. European Society for Organ Transplantation (ESOT).

The Assembly chairman invites Eurotransplant's president, Prof. Bruno Meiser to announce the 2012 winner. Prof. Meiser together with Mrs. Hanneke Siebers, the widow of the late secretary/treasurer, Henk Schippers, present

**Dr. Sebastiaan Heidt from the  
Department of Immunohaematology  
and Blood Transfusion  
Leiden, University Medical Center,  
the Netherlands**

with the 2012 Henk Schippers Young Investigators award. Dr. Heidt is congratulated with this prize and is invited to present his data during the Eurotransplant winter meeting in Alpbach (Austria), January 2013.



## EUROTRANSPLANT

### Announcement of the winner of the Eurotransplant 45th anniversary award

Prof. Meiser announces that the Board of Eurotransplant had decided to grant the ET's 45th anniversary award to

#### Dr. Mirela Bušić from Zagreb, Croatia

She was honored with this prize for her outstanding efforts to realize Croatia's full membership of ET, her dedication to the field of organ donation, allocation and transplantation as well as for her valuable contributions as a member of the Eurotransplant International Board.

In her words of thanks Dr. Bušić mentioned that she dedicated this well appreciated award to all her colleagues as well as to the Croatian people, as without their commitment resp. their positive attitude towards organ donation the ET full membership as well as the high donation rate in Croatia would never have been achieved.

The following presentations were also given during the Assembly:

- Presidential address by Prof. 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 ET Winter Meeting January 23-25, 2013 – Alpbach, Austria

The 2013 edition of ET's Winter Meeting in Alpbach, Austria, was well attended by 150 participants from 10 different European countries. This year the program was adapted compared to previous years into a scientific program with workshops and plenary sessions starting 09.30 am until 08.00 pm on Thursday and from 09.30 am until noon on Friday.



## Jubilee

The kick-off of the meeting took place in Hotel Alpbacherhof on Wednesday, January 23 with a welcome dinner. In a short speech, ET's Medical Director, Axel Rahmel, informed participants that this year we celebrate that ET organizes the winter meeting for the 30th time. Based on the fact that ET's Winter Meeting has been organized for so many years and is always well attended, we can conclude that it is of high value for professionals in organ donation and transplantation, doctors as well as government officials. At ET's Winter Meeting, the relaxed and inspiring ambiance proves to provide the right conditions for meeting each other, discussing actual developments and exchanging experiences.

## Scientific Program – January 24, 2013

On the first meeting day, various workshops were organized to discuss recent developments and issues for different organs (heart, lungs, kidney, pancreas, liver). Furthermore, ET's Information Services/Registry staff provided training-on-demand, answered questions and discussed wishes of users of ET's software applications. A special workshop was devoted to the ethical issues around brain death diagnostics in various ET member states and other European countries. Representatives of the governments of ET member states discussed in a workshop organized by the ET Council the various measures that were taken with regard to the recent data manipulation in Germany of patients awaiting a liver transplantation over . Special attention was given to the proposed measures in the area of additional inspection and audits that other member countries might decide to organize as well. Also the desired support from ET with regard to providing and collecting data for inspections/audits was discussed.

## Annual figures 2012

The winner of the 'Henk Schippers Young Investigators Award 2012', Dr. Sebastiaan Heidt from Leiden University Medical Center in the Netherlands, gave his presentation at the Plenary Session. ET's Annual figures of 2012 were presented by Prof. Axel Rahmel, Medical Director of ET. He showed that international cooperation within ET, truly is of life-saving importance, especially for special patient groups (such as high urgent, highly immunized patients). He also demonstrated the decrease in the number of donors in Germany in 2012 by over 10% which has been for a large part compensated by increase of donor numbers in other ET countries. All figures for 2012 are uploaded in ET's Statistics Library (<http://statistics.eurotransplant.org>) and are available online. Furthermore, ET issued a press release on January, 25 with the most important annual figures and explanation of data.

## Plenary Session – January 25, 2013

The second day of the meeting started with a walk through the snow to the Congress Center where a plenary session took place. This included a presentation on the outcome of a study for high urgent kidney patients in which ET participates. Pancreas and intestine transplantation was addressed in a presentation showing the benefits of shared experience in simultaneous intestine and pancreas procurement. It is recommended that intestine procurement is being performed by a transplant surgeon who is experienced in intestine explantation preferably in presence of a surgeon who is involved in pancreas procurement. This presentation supported a recommendation by the EPAC/ELIAC that was approved by the ET Board during its meeting that took place two days before. A Hungarian representative shared with the participants their experiences with the 'preliminary membership'. It was explained that the cooperation with ET resulted in a strong stimulation of the national transplant program, with e.g. a considerable increase in the number of heart transplantations. The program furthermore included a presentation on a research project regarding normothermic resuscitation for various organs that is supported by the European Commission. Finally, there was a "farewell" speech by Prof. Günter Kirste, Director of the German Deutsche Stiftung Organtransplantation (DSO) who was about to retire. In his presentation he memorized the significant developments in organ donation in Germany over the past years. The conference was closed by ET's President Prof. Bruno Meiser who thanked both speakers as well as participants for their input and active participation in the discussions and dialogues.



# Announcement of the 2013 Henk Schippers Young Investigator Award



Henk Schippers became the first Eurotransplant Director in 1970. After 5 years, he was appointed Secretary Treasurer of the Board until his death in 2003. Henk laid the foundations for the administration of Eurotransplant. He successfully completed negotiations with the insurance companies and initiated the international

network, which is now a hallmark of Eurotransplant. To commemorate his pioneering work for Eurotransplant a young investigator award in his name was established in 2003.

## Purpose

The purpose of this award is to encourage young clinical and/or scientific investigators to pursue a career in the field of organ and tissue transplantation. It is our hope that this research will be invigorated by the work of young, talented individuals supported by stable multi-year funding. The Henk Schippers Young Investigator Award is especially meant to enable the investigator to present his/her results of clinical and/or scientific organ transplantation related investigations at well recognized and respected international transplantation congresses or symposia, e.g. European Society for Organ Transplantation (ESOT).

## Eligibility

Candidates (< 40 years) must have attained a masters or PhD degree. Individuals at the Associate Professor level are not eligible. Clinicians and investigators must have completed their residency or post-doctoral training no more than five years prior to applying. Applications coming from the entire European area will be accepted.

## Terms

The recipient will receive € 2.500. This award will be made available to the individual applicant and must be used for direct expenses. A progress report will be required. Applicants can provide a paper, also after presentation at a specific meeting and the candidate chosen can use the money in the next year. The Eurotransplant International Foundation will retain the right to unilaterally cancel any awards for non-compliance or non-performance.

## Application procedure

Candidates must submit:

- A completed curriculum vitae;
- An application letter with
  - the publication on which the application is based
  - for which purpose he/she will use the award with a short description of the research project (limited to three pages);
- A list of publications abstracts and previous research in the field of transplantation (limited to two pages);

- Applications must also contain a letter of nomination from a faculty sponsor who will accept responsibility for monitoring the awardee;
- Applications must be entirely in the English language.

One original and one copy of all parts of the application must be received on or before the due date at the office of Eurotransplant International Foundation in Leiden, the Netherlands.

At least one copy of the application must contain original signatures.

Non-complying applications will be returned without review.

## Deadline

☞ The application deadline is May 31, 2013

## Selection

The Award Committee consisting of Board members of the Eurotransplant International Foundation, will consider all proposals. Decisions of the Award Committee will be announced by the **second week of September**.

The award will be presented at the annual Assembly / Presidential Symposium of Eurotransplant. The winner of the award will be invited to present his/her data (15 minutes talk including discussion) either at the annual Presidential Symposium or at the annual ET Winter Meeting. Travel costs will be reimbursed.

## Award management

Award payments will be made following written acceptance by awardee.

## Change in status of awarded

Awards are to remain solely with the designated awardee and may not be transferred to any other person. If a recipient decides not to attend the anticipated congress, the award will be terminated as described above.

## Inquiries

Direct all inquiries to:

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## Introduction new ET employees



### **Juliëtte van der Laan, Manager Communications**

It is a great pleasure to introduce myself as the new Manager for both internal and external communication at Eurotransplant. The past 11 years I was responsible for strategic communication management and the communication team at NRG (nuclear research and medical isotopes production) and acted as Chairwoman of the Nuclear Information Committee Europe. On September 1, I joined Eurotransplant where I am responsible for, amongst others, reputation and issues management, internal communication, press contacts and development of a broad range of communication and information tools (web, print, meetings).



### **Marieke van Meel, International coordinator Follow-Up Registries**

I am coordinator of Eurotransplant's present Follow-Up Registries and working on the development of three new Follow Up applications for Lung, Heart and Kidney Follow-Up. I am also responsible for international data-exchange with other Follow-Up Registries, ESDP Study coordination, policy development & PR for Eurotransplant's Registry. I previously worked as Policy Officer for Rare Diseases at VSOP. In my free time I work as a volunteer as chairwoman of the patient-driven organization for Care and Cure for patients suffering from Nephrotic Syndrome, NephEurope. In addition to this, I also act as Scientific Advisor for EurenOmics Project.



### **Maaïke van Hennik, Coordinator organizational development and quality**

After developing Eurotransplant's Registry department for the past 4 years, I accepted the position of Coordinator organizational development and quality in 2011. In this position, I am responsible for monitoring of (audit-)cycles related to implemented standards within ET (i.e. ISO) and I lead or support the development of supra-departmental processes within Eurotransplant. My tasks include sustaining and developing Eurotransplant's quality assurance system, supporting the planning and control cycles and advising management and employees with regard to the development and execution of strategy and quality assurance.



### **Liesbeth van Klarenbosch, Business Analyst**

After completing a Master's Degree in Computer Science (MSCS), I have several years of working experience in Software Engineering, a medical hospital included. Before joining Eurotransplant, I worked as Lecturer and Coordinator Software Engineering at Leiden University of Applied Sciences. As a business analyst I translate the need of the business to ICT-solutions with special focus on process analysis, functional requirements, project management techniques and information security (NEN 7510).



### **Adrie Rozendaal, Enterprise Architect**

After my study in biochemistry, theoretical chemistry and philosophy of science, I preferred a career in the fast growing ITC environment. I held various positions dedicated to the area between organization and information. Previously, I was employed as a business consultant and enterprise architect in banking and finance (Rabobank). On October 1, 2012 I started in my new position at Eurotransplant where I will set up an enterprise architecture and support the organization, growing towards a mature architecture-based development discipline.



### **Peter Ribbers, Team Leader Systems Development**

My name is Peter Ribbers, Team Leader of the Systems Development department. I joined Eurotransplant a few months ago after a career in software development, team leadership and entrepreneurship. It is my responsibility to coordinate the software development activities, both in functional and technical aspects and to coach the team members in their work. Our goal as a team is to continuously improve our software and the way we develop it, so that we can give maximum support to the transplantation processes.

# Reminder – ET general phone number

ET changed its general phone number. In order to be able to serve you as our valued contact partner as quick as possible, we kindly ask you to note down our new phone number in your systems (including cell phone):

- General phone: +31-71-5795700 (*for helpdesk, medical administration, staff, operator*)
- Allocation center: +31-71-5795888 (*please only use during allocation procedures*)

Using our 'old' phone number will bring you in touch with the Dutch Transplantation Society and NOT with Eurotransplant which might cause delay in your phone contacts with us.



## We kindly thank you for your cooperation!

## Release notes – first release 2013

### *Implementation of scheduled updates in ENIS and related applications*

On March 11, 2013 in the early morning hours between 05:00 and 07:00 am, the first scheduled 'release' of 2013 took place, wherein Eurotransplant (ET) updated the ENIS and its associated applications (DPA, donor reports, follow-up, etc.). During this release following changes were implemented:

### **Organ(s)**

#### *Liver*

\* [ET-6148] – Some adaptations have been done for the liver in ENIS to improve the quality of data entrance. A pop up will appear during entering Creatinine, Bilirubin and INR when:

- Creatinine is higher than 244 umol/l or 2.76 mg/dl
- Bilirubin is higher than 277 umol/l or 16.2 mg/dl
- INR is higher than 2.10.

In this case, the data still can be saved.

There was also an adaptation in the recipient liver profile: Drug abuse is now called 'IV Drug abuse'.

### **Applications**

#### *ENIS*

\* [ET-6060] – There has been an adaptation of the screens 'Antibody screening per recipient' and 'Antibody screening per center'. Luminex has been added to the list of values of 'Screen Type'.

### **Registry**

#### *Kidney follow-up*

\* [ET-6025] – The second part of the project Certain has been completed. This is the exchange of follow-up data for participating kidney centers between Certain and Eurotransplant.

\* [ET-6034] – ESDP application: an automatic e-mail will be generated in month five after transplantation. After month six after transplantation a serum sample for DSA (Donor Specific Antibodies) screening has to be sent to the ETRL laboratory.

\* [ET-6145] – For the project Certain: there was a problem sending data when a recipient had no Nationality in ENIS. This problem has been solved.

*Release 2-2013 is currently scheduled for May 21, 2013*

# News from the ET Infrastructure Department

## Upgrade of IT systems

In February/March 2013 Eurotransplant's IT Department started a substantial upgrade of its IT hardware, in order to extend the capacity of the IT networks and to prepare it for future increased use and back-up availability. This upgrade involves installation of new modern servers including migration from the Oracle data base server to a new operating system. The changeover from current 'server equipment' for modern and larger 'server equipment with additional network facilities' is unfortunately impossible without bringing systems temporarily down. Bringing systems down – and after upgrading installations back-up again – is performed in a controlled way and scheduled at hours where there is minimum use and impact for users. Before every 'outage period' users are informed via email and/or announcements on the ET member site.

During the recent upgrade activities, ET was confronted with some unforeseen technical problems with the new hardware. This made it necessary to bring more systems down for short periods of time and also more frequently than was planned and foreseen. We hope you did not experience any delay or disruptions in your contacts with ET during these outages. Our allocation staff is well trained and, in consultation with you, able to run allocation procedures in a 'manual way' when systems are unavailable. We currently expect more short periods of system outage will be necessary before all new hardware is performing in the desired and expected way.

We thank you for your kind understanding and should you have questions and/or when you require more information, please phone our office: +31 71 5795700.

# Eurotransplant Statistics Report Library

Eurotransplant (ET) frequently receives data requests from many stakeholders, such as transplant professionals, lay-people, journalists, etc. These requests often concern questions about numbers of donors, numbers of transplanted patients and organs, numbers of patients on the waiting list as well as general demographics regarding such general statistical information. Up till recently, all data requests were individually processed by the ET medical staff. With the introduction of the comprehensive ET Statistics Report Library, data requests regarding general statistical information are directly available for our transplant professionals. The ET Statistics Library is an extensive, centralized, on-line collection of reports covering most aspects of ET's activities. There are reports on waiting list dynamics (registrations, periodic numbers, removals), on donation, and on the allocation and transplantation of organs (deceased and living donor), showing primarily data by year and by country, but also by month or by center. Data is provided in tabular format, but also in an increasing number of graphs, showing trends over the last 10+ years.

The reports are accessible at <http://statistics.eurotransplant.org>, where a web application allows the user to locate relevant reports in numerous categories, based on type (e.g. donors, waiting list, transplants), organ, year, country and characteristic (e.g. blood group, age, urgency). It is then possible to view and browse through the relevant reports or to download them in pdf or xls formats.

For *Members*, after logging in, there are many more detailed reports available, and also center specific reports (for member's own center).

Different versions of a report are created automatically, for each center, country, year or organ, as appropriate. Reports are also automatically and periodically updated, weekly, monthly or yearly as needed. Yearly reports are refreshed several times a year to reflect modifications or additions to the data and reports with year cumulative numbers are updated monthly, so the data in the library as a whole is kept up-to-date.

The ET Statistics Report Library was introduced at the Annual ET meeting in October 2012. Since then there have been hundreds of views and downloads per week and the number of available reports in the library has doubled. There will be continual additions to the library, so increasing the transparency of ET activities, providing the community, with a useful tool and source of information.







## Mark your calendar

The Eurotransplant Annual Meeting 2013 will take place on  
October 10 and 11 in Leiden, the Netherlands



## Calendar of Events

### 20TH ANNUAL MEETING OF THE BELGIAN TRANSPLANT SOCIETY (BTS)

March 21, 2013  
Brussels, Belgium  
For information visit [www.transplant.be](http://www.transplant.be)

### 3RD ETHICAL LEGAL AND PSYCHOSOCIAL ASPECTS OF ORGAN TRANSPLANTATION (ELPAT) CONGRESS

April 20 – 24, 2013  
Rotterdam, the Netherlands  
For information visit [www.esot.org](http://www.esot.org)

### 33RD ANNUAL MEETING OF THE INTERNATIONAL SOCIETY FOR HEART & LUNG TRANSPLANTATION (ISHLT)

April 24 – 27, 2013  
Montreal, QC, Canada  
For information visit [www.isHLT.org](http://www.isHLT.org)

### 50TH EUROPEAN RENAL ASSOCIATION – EUROPEAN DIALYSIS AND TRANSPLANT ASSOCIATION (ERA-EDTA) CONGRESS

May 18 – 21, 2013  
Istanbul, Turkey  
For information visit [www.era-edta2013.org](http://www.era-edta2013.org)

### AMERICAN TRANSPLANT CONGRESS (ATC)

May 18 – 22, 2013  
Seattle, USA  
For information visit [www.atcmeeting.org](http://www.atcmeeting.org)

### 19TH ANNUAL CONGRESS OF THE INTERNATIONAL LIVER TRANSPLANTATION SOCIETY (ILTS)

June 12 – 15, 2013  
Sydney, Australia  
For information visit <http://2013.ilts.org/>

### 16TH CONGRESS OF THE EUROPEAN SOCIETY FOR ORGAN TRANSPLANTATION (ESOT)

September 8 – 11, 2013  
Vienna Austria  
For information visit [www.esot.org](http://www.esot.org)

### 14TH WORLD CONGRESS OF THE INTERNATIONAL PANCREAS & ISLETS TRANSPLANTATION ASSOCIATION (IPITA)

September 24 – 27, 2013  
Monterey-CA, USA  
For information visit [www.ipita2013.org](http://www.ipita2013.org)

### EUROTRANSPLANT ANNUAL MEETING 2013

October 10 & 11, 2013  
Leiden, the Netherlands  
For information: Ms. Margita Lobry  
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Ph: +31 71 5795700; Fax: +31 71 5790057  
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[www.eurotransplant.org](http://www.eurotransplant.org)

### 22. JAHRESTAGUNG DER DEUTSCHEN TRANSPLANTATIONSGESELLSCHAFT (DTG)

October 24 – 26, 2013  
Frankfurt, Germany  
For information visit [www.dtg2013.de](http://www.dtg2013.de)