



# European Liver Transplant Registry

A service of the European Liver and Intestine Transplant Association (E.L.I.T.A)



A section of the European Society of Transplantation (E.S.O.T)



## History and Aim

The idea of a European Liver Transplant Registry (ELTR) was brought up at the meeting of the European Society for Organ Transplantation (ESOT) [www.esot.org](http://www.esot.org) in Munich, 1985. A group including the main liver transplant Centers decided to create the ELTR with the following objectives:

1. Registry of all adult and pediatric liver transplantation (LT) procedures in Europe
2. Link between European LT Centers
3. Scientific use and publications.

Paul Brousse Hospital (Villejuif, France) was designated to manage and analyze the data of ELTR since its creation in 1985. Two years later, ELTR had collected information on all LT recipients from 32 European centres (Lancet, 2: 674, 1987) and since 1991 from 67 centres (Transplant Proc, 21: 2383, 1991). Between 1968 and June 2009, the ELTR has collected data regarding 87959 LTs performed in 143 centres from 25 European countries. In 1993, the ELTR has become a service of the European Liver and Intestine Transplant Association (ELITA) [www.elita.org](http://www.elita.org).

## Coordinating Committee

A two parts questionnaire (Report of LT and Follow-up report) was established by the ELTR Coordinating Committee (ELTR-CC). A standardized and computerized method for data entry has been developed to collect accurate and uniform data in all liver transplants across the European participating centres. Each Centre participates by sending all the requested LT data and the follow-up of the recipients.

The ELTR-CC is responsible for maintaining the data collection system, monitoring the quality of the data, and for statistical data analysis. The ELTR updating is made twice a year (at June 30th and December 31st). Data Analysis Booklets with adult and pediatric figures are then published and transmitted to all the participating centres. A set of updated PP slides is put in the website [www.eltr.org](http://www.eltr.org) at the disposal of the

authorized users (cf. "Data communication and Publication"). Periodical meetings are organized by the ELTR-CC to review the data and to discuss topics of scientific and clinical interest. The ELTR Coordinating Committee is composed of:

Chairman	René ADAM, MD, PhD.
Data Manager	Vincent KARAM, PhD.
Biostatistician	Valérie DELVART
Secretary	Vanessa Kretzschmar

## Data Management and quality Control

### 1. Questionnaire, Database and Data transfer

Participation to the Registry is voluntary. A standard questionnaire was established by the ELTR Experts Committee (ELTR-EC). The first part of the questionnaire includes data on LT indication, donor and recipient, technical aspects of LT (live donation, split liver, domino transplant, Non heart beating donors,...), and the initial immunosuppression. The second part concerns the patient follow-up and contains questions on the cause of death or graft failure and the maintenance immunosuppression. To encourage completion, the questionnaire was intentionally limited to the main items. A standard database for data entry has been developed and provided to all contributing Centres with an instruction handbook to collect accurate and uniform data. To avoid spelling and typing errors, most of the items are pull-down menus except the name of patients, dates and laboratory values. A copy of updated electronic file is sent to the ELTR-CC twice a year.

### 2. Data validation

A logic control procedure has been developed. The data are subjected to checks for completeness, consistency, and range. Comprehensive logical intra- and inter-updates are performed. A list of the queries is communicated to the Centre's personnel in charge of data management each time a new update comparison is performed. The Centre performs the corrections and submits a new file. In addition, the ELTR has established agreements with the



European Organ Sharing Organizations (OSO). United Kingdom Blood and Transplant Authority, the Spanish "Organización Nacional de Transplantes", the Scanditransplant (Denmark, Finland, Norway and Sweden), Eurotransplant Foundation (Austria, Belgium, Croatia, Germany, Luxembourg, Netherlands and Slovenia), The deutch "Nederlandse Transplantatie Stichting", and the French "Agence de la Biomédecine". The purpose of this agreement is to exchange data collected from European Centres.

### 3. Data analysis

Data are analyzed with Statistical Analysis System (SAS). The dynamics of data control are continued during the statistical analyzes. Editing and referral to clinical records are used when necessary to resolve any inconsistencies that are detected during the analysis. Most of the studies in which ELTR data is analyzed require calculation of graft and patient survival rates. These are determined by actuarial methods and the statistical significance is determined by the logrank test to compare survival curves. Regression methods are also used to identify risk factors associated with LT. The ELTR is also a pediatric database and a specific routine data analysis concerns this population of patients

A Centre specific data analysis is done once a year and five figures are put in a password protected area of the website:

1. Patient and graft survival
2. Patient survival according to the three main indications
3. Distribution of primary indications
4. Patient survival according to recipient age, and
5. Causes of mortality following the first LT.

In case a contributing centre needs additional analyses, a specific data request can be submitted directly to ELTR office or *via* the ELTR web site.

### 4. Experts Scientific Committee and Workshops

Periodic meetings are organized by the ELTR Expert Committee to review the questionnaire and to discuss topics of scientific and clinical interest. The expert Committee is composed of hepatologists and surgeons, which discuss each item of the questionnaire and validate the data entry masks and the instruction handbook. Periodic workshops

are also organized and all of the persons in charge of the updating of ELTR data (Transplant Coordinators, Data Managers, OSO representatives,) who are invited to give their comments and to report problems.

The ELTR-EC and the workshops permit to adapt the questionnaire to the evolution of LT, in order to provide an updated evaluation of LT results.

### 5. Audit visits

To compare information contained in the report with original source documents or database, additional measures have been taken and include site visits to the Centres. In 1997, the ELTR coordinating team appointed an independent committee:

Vincent KARAM, France  
Bridget GUNSON, UK  
Francine ROGGEN, Belgium  
Wolfgang WANNOFF, Germany  
Juan Carlos MENEU DIAZ, Spain  
Baltasar PEREZ SOBREDO, Spain

to perform the audits according to a predetermined standard methodology. Ten randomly selected centres are visited per year. The audit visits also allow resolution of any centre-specific problems that may have arisen and define guidelines to prevent further errors. A confidential audit report is sent to the head of the Centre with the list of inconsistencies.

### Data Communication and Publications

The ELTR is increasingly present in scientific congresses with more than 10 communications per year during the last 3 years. The ELTR has also published 22 peer-reviewed papers in the main scientific journals. The list of communications and publications is available in the appendix.

ELTR created in 1997 a website [www.eltr.org](http://www.eltr.org) that is continuously updated. The ELTR website contains the following information:

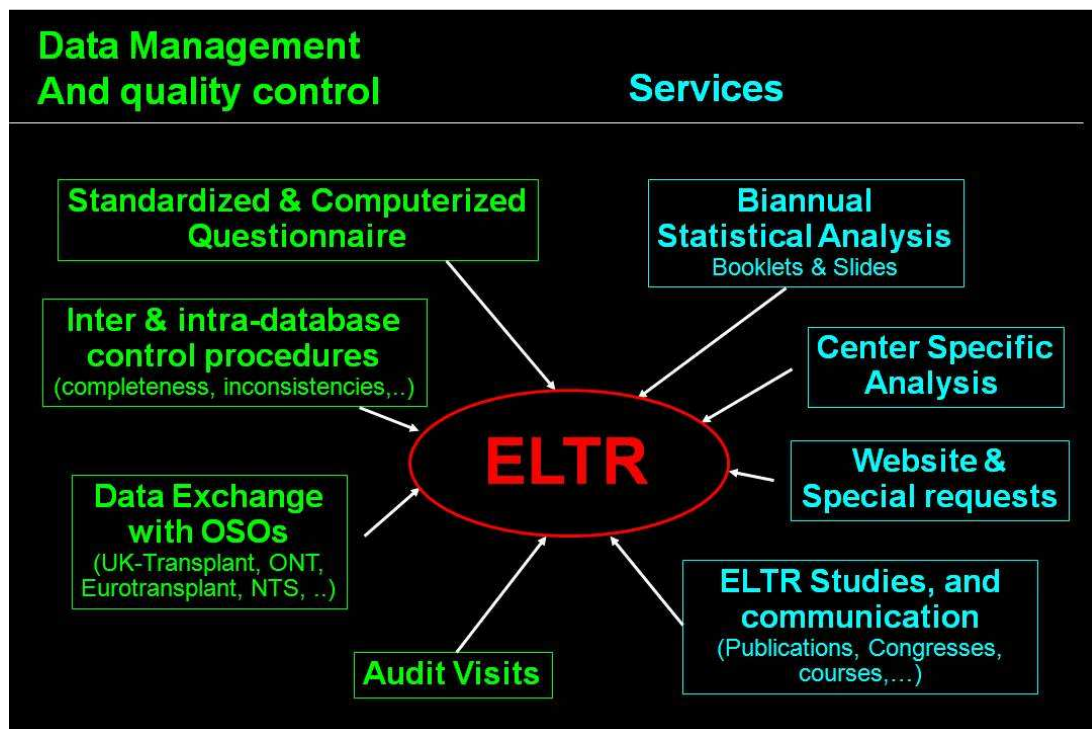
- News (Audit visits, ongoing studies, ELTR events...)
- ELTR purpose and description of the procedures
- Updated list of contributing centres
- Data analysis results (52 figures and slides)
- Biannual centre Specific analysis (pw protected pdf)
- ELTR conventional slides (pw protected)
- Online data request form
- List of publications
- Links



### Funding

From its inception the ELTR has been funded by money raised by individuals in the liver transplant community channeled through ELITA and the Paul Brousse University Hospital. Biomedical companies also participate with unrestricted educational and yearly grants.

The size, completeness and continuous validation of the database, now warrant an improved financial structure. Both ELTR and ELITA officers with the backing of ESOT council are seeking funding structures to maintain, continue and expand the ELTR – the only pan European database on liver transplantation in Europe. It is a European resource of very great importance for scientific research, patient safety, professional audit, and for information on results of donation.



### Summary of the ELTR procedures and services



### Publications

- 1- Hepatic transplantation in Europe : first report of the European Liver Transplant Registry. Bismuth H. et al. ([Lancet 1987](#))
- 2- Liver Transplant Registry Report. Gordon RD, Bismuth H. ([Transplant Proc 1991](#))
- 3- Normalised intrinsic mortality risk in liver transplantation: European Liver Transplant Registry Study. Adam R. et al. ([Lancet 2000](#))
- 4- Quality control of the European Liver Transplant Registry: results of audit visits. Karam V. et al. ([Transplantation 2003](#))
- 5- Quality control of transplant registries. Morris P, Monaco A. ([Transplantation 2003](#))
- 6- Assessing the quality of data in a transplant registry: The European Liver Transplant Registry. Van der Meulen J, Jacob M, Copley L. ([Transplantation 2003](#))
- 7- Evolution of liver transplantation in Europe: report of the European Liver Transplant Registry. Adam R. et al. ([Liver Transplantation 2003](#))
- 8- Liver transplantation in Europe: is there a room for improvement? Adam R., Luccidi V., Karam V. et al. ([J Hepatology 2005](#))
- 9- Liver transplantation for Budd-Chiari syndrome: A European study on 248 patients from 51 centres. Mentha G. et al. ([J Hepatology 2006](#))
- 10- Liver Transplantation for Hereditary Hemorrhagic Telangiectasia: Report of the European Liver Transplant Registry. Lerut J. et al. ([Annals of Surgery 2006](#))
- 11- Impact of donor age and year of transplantation on graft and patient survival following liver transplantation for hepatitis C virus. Mutimer DJ. et al. ([Transplantation 2006](#))
- 12- 3-month and 12-month mortality after first liver transplant in adults in Europe: predictive models for outcome. Burroughs A. et al. ([Lancet 2006](#))
- 13- The place of liver transplantation in Caroli's disease and syndrome. De Kerckhove L. et al. ([Transplant International 2006](#))
- 14- Liver transplant in cystic fibrosis: a poll among European centers. A study from the European Liver Transplant Registry. Melzi ML. et al. ([Transplant International 2006](#))
- 15- Living liver donor mortality: where do we stand? Bramstedt KA. et al. ([Am J Gastroenterology 2006](#))
- 16- Documented deaths of hepatic lobe donors for living donor liver transplantation. Trotter JF et al. ([Liver Transplantation 2006](#))
- 17- The place of liver transplantation in the treatment of hepatic epitheloid hemangioendothelioma: report of the European liver transplant registry. Lerut J. et al. ([Annals of Surgery 2007](#))
- 18- Towards a better liver transplant allocation system. Burroughs AK, et al. ([Liver Transplantation 2007](#))
- 19- Liver transplantation for primary and metastatic liver cancers. Hoti E and Adam R ([Transplant International 2008](#)).
- 20- Liver transplantation for alcoholic liver disease in Europe: A study from the ELTR. Patrizia B. et al. ([Am J Transpl. 2009](#)).
- 21- Liver transplantation: the current situation. Adam R and Hoti E. ([Seminars in Liver Disease 2009](#))
- 22- Long term outcome of patients transplanted for autoimmune hepatitis -Analysis of the European Liver Transplant Registry. Schramm C. et al. ([submitted to Liver Transplantation](#)).



## APPENDIX

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### Communications

#### 2000

- ELTA-EASL Meeting on Liver Transplantation, Rotterdam, Apr., 2000 - Results of liver transplantation. ELTR report.
- 5th Postgraduate Course on Hepatobiliary Surgery, Padova, Dec. 2000 - Results of liver transplantation according to ELTR.

#### 2001

- ILTS-ELTA-LICAGE, Berlin 2001 - Evolution of liver transplantation in Europe; report of the European Liver Transplant Registry (ELTR).
- 10th Congress of the European-Society-for-Organ-Transplantation, Oct 2001, Lisbon, Oct. 2001 - « Registry report ».

#### 2002

- 5th IHPBA World Congress, Tokyo, Apr. 2002. 1- Liver transplantation: Evolution of graft loss by chronic rejection in Europe. A report from the ELTR. 2- Liver transplantation: Current results of living-related liver transplantation (LRLT) in Europe. Report from the ELTR.

#### 2003

- Symposium New therapeutic options in liver & intestine transplantation ESOT 20/09/2003 Venezia (Italy) - Living related donor liver transplant, ELTR registry.

#### 2004

- Finnish Society of Transplant Surgeons, Helsinki (Finland), Jan. 2004. - Presentation of the ELTR (Data and audit results)
- 10th Anniversary of the Adult-to-Adult Living Donor Liver Transplantation Symposium, Tokyo (Japan), Feb. 2004 - Living Related Liver Transplantation in Europe: Report of the European Liver Transplant Registry.
- IHPBA World Congress, 2004. (Abstracts published in HPB 2004; 6, Suppl. 1) - Living related liver transplantation (LRLT) in Europe: report of the European Liver Transplant registry (ELTR).

#### 2005

- 40th Annual Meeting of the European-Association-for-the-Study-of-the-Liver, Apr. 2005 Paris, France. (Abstracts published in: Journal of Hepatology, Vol. 42 Suppl. 2 Apr 2005.) - Liver transplantation: Predictive models for 3 and 12 month survival based on the ELTR registry
- 11th Annual Meeting of the International Liver Transplant Society (ILTS), July 2005, Los Angeles, USA. (Abstracts published in : Liver Transplantation, Vol. 11 n°7) - Liver transplantation: Predictive models for 3 and 12 month survival based on the ELTR registry.
- 12th Congress of the European Society of organ Transplantation ESOT, Geneva, Oct. 2005. - State of the Art - ELTA Plenary session: ELTR Registry - 1400 European live donor liver transplants: results of prospective donor audit.

#### 2006

- 13th Annual Meeting of the European Surgical Association, Zurich, April 2006. - Liver transplantation for hereditary hemorrhagic telangiectasia: Report of the European liver transplant registry. (Abstracts published in: Annals of Surgery 2006 Dec.; 244(6):854-62; discussion 862-4.)
- 7th world congress of IHPBA, Edinburgh, Sept. 2006. (Abstracts published in HPB, Vol8 Suppl2, Sept. 2006.) 1- Liver transplantation for HCC in Europe: analysis of 8086 cases. 2- Living donor liver transplantation: a European Liver Transplant Registry (ELTR) report on 1709 cases. HPB 2006; 8 (Suppl. 2) : 35. 3- Evolution of Liver transplantation in Europe: Report of 63430 transplants in the European Liver Transplant Registry (ELTR).
- 2006 Joint International Congress of ILTS, ELITA, LICAGE; May 2006, Milan, Italy. (Abstracts published in : Liver transplantation 2006 ; 12(5) - Outcome of split liver transplantation in Europe (ELTR data base).

#### 2007

- 42nd Annual Meeting of the European Association for the Study of the Liver, Barcelona, April 2007. (Abstracts published in: Journal of Hepatology 2007; 46 Suppl. 1) - Outcome of patients transplanted for primary sclerosing cholangitis - analysis of the European Liver Transplant Registry.



- 3rd ELITA-ELTR Winter-meeting. Obergurgl Tyrol, Mars 2007. (Abstracts published in Transplant International, vol 20 suppl 1, April 2007). 1- Interest of the new items of the ELTR questionnaire. The New Database. 2- Outcome of patients transplanted for primary sclerosing cholangitis - analysis of the European Liver Transplant Registry (ELTR).
- Journées Francophones de pathologies digestives, mars 2007, Lyon, France. (Abstracts published in: Gastroentérologie Clinique et Biologique 2007 ; 31 ; Hors Série II) - Transplantation hépatique avec donneur vivant en Europe : étude du Registre Européen de Transplantation (ELTR) sur 1942 patients.
- 14th Annual Meeting of the European Surgical Association, Dublin, April 2007. - The Place of Liver Transplantation in the Treatment of Hepatic Epitheloid Hemangioendothelioma: Report of the European Liver Transplant Registry. (Published in: Ann Surg. 2007 Dec; 246(6):949-957.)
- Annual American Transplant Congress, May 2007, San Francisco, USA (Abstracts published in: American Journal of Transplantation, Vol. 7 Suppl. 2) - Liver transplantation (LT) for hereditary hemorrhagic telangiectasia (HHT): Report of the European liver transplant registry (ELTR).
- 13th Annual International Congress of the ILTS, Rio de Janeiro, June 2007. (Abstracts published in: Liver Transplantation 2007 ; 13 n6 Suppl. 1) - Outcome of patients transplanted for alcoholic liver disease - analysis of the European Liver Transplant Registry (ELTR).
- ESOT, Prague, Oct. 2007. (Abstracts published in Transplant International, Vol 20 Suppl. 2, Sept. 2007). 1- Outcome of clinical trials and registry data: consensus or conflict? 2- 15-year evolution of liver transplantation in Europe. 3- Living donor liver transplantation: a European liver transplant registry (ELTR) report on 1942 cases. 4- Liver transplantation for intrahepatic recurrence of hepatocellular carcinoma in non-cirrhotic livers after partial liver resection. 5- Liver transplantation for hereditary hemorrhagic telangiectasia (HHT): Report of the European Liver Transplant Registry.

## 2008

- IHPBA. India, Mumbai, Feb. 2008. (Abstracts published in HPB, Vol 10 Suppl. 1). 1- 15-year evolution of liver transplant in Europe. 2- Living donor liver transplantation: a European Liver Transplant Registry (ELTR) report on 2043 cases.
- ELITA Winter Meeting, Cortina D'Ampezzo, Italy, Avril 2008. (Abstracts published in Transplant International, Vol. 21 suppl. 1, April 2008). 1- Non tumor related prognostic factors of liver transplantation for HCC. 2- 15-year evolution of liver transplantation in Europe. 3- Quality control of the European Liver Transplant Registry (ELTR). Report of the Living Donor Liver Transplantation audit.
- 43rd Annual Meeting of the European Association for the Study of the Liver, April 2008, Milan, Italy (Abstracts published in: Journal of Hepatology, Vol. 48 Suppl. 2). - Long term outcome of patients transplanted for autoimmune hepatitis - Analysis of the European Liver Transplant Registry.
- 8th American Transplant Congress, May 2008 2008, Toronto, Canada. (Abstracts published in: American Journal of Transplantation; Vol 8 Suppl. 2 May 2008). - Liver transplantation (LT) for alcoholic liver disease in adults in Europe. - Hepatic angiosarcoma (HAS): The last absolute contra-indication to liver transplantation (LT) report of the European liver transplant registry (ELTR).
- ILTS International Congress, Paris, France, Juillet 2008. (Abstracts published in: Liver transplantation, Vol. 14 Suppl. 1). - Living donor liver transplantation: a European liver transplant registry (ELTR) report on 1942 cases. - 15-year evolution of liver transplantation in Europe. - Quality control of the European Liver Transplant Registry (ELTR). Report of the living donor liver transplantation (LDLT) audit. - Hepatic angiosarcoma (HAS): The (last) absolute contra-indication to liver transplantation? Report of the European Liver Transplant Registry (ELTR).

## 2009

- The Liver Meeting 2009 - 60th Annual Meeting of the AASLD Boston, USA, 30 Oct. - 3 Nov. 2009. (Abstracts published in: Hepatology 2009; 50(4 Suppl.): 562A). - Liver transplantation in polycystic liver disease: Excellent survival and improvement of quality of life.
- 14th congress of the European Society for Organ Transplantation (ESOT) Paris, France, 30 August - 2 September 2009. (Abstracts published in: Transplant International 2009; 22(Suppl. 2):330). - Risk factors of liver transplantation and donor to recipient matching: impact on outcomes in the European Liver Transplant Registry (ELTR). - Quality control of the European Liver Transplant Registry (ELTR). Report of the Living Donor Transplantation Audit. - Living donor liver transplantation: A European Liver Transplant Registry (ELTR) report on 2634 cases - Current status of liver transplantation in Europe: An analysis of ELTR Data.
- The 2009 International Congress of ILTS. New York, USA, 8-11 July 2009. (Abstracts published in: Liver Transplantation 2009; 15(7 Suppl. 1):S92 (O68)). - Living Donor Liver Transplantation: A European Liver Transplant Registry Report on 2364 cases. - 20-year evolution of liver transplantation in Europe. Report of the European Liver Transplant Registry (ELTR).
- 5th ELITA - ELTR Winter Meeting. Are, Sweden, 19-21 March 2009. (Abstracts published in: Transplant International 2009; 22(Suppl. 1):11). - Liver transplantation in isolated polycystic liver disease.
- Journées Francophones d'Hépatogastroentérologie et d'Oncologie Digestive (JFHOD) Paris, France, 19-22 Mars 2009. (Abstracts published in: Gastroentérologie Clinique et Biologique 2009; 33 (Hors Série 1):A 4 (CO 08)). - Transplantation hépatique avec donneur vivant en Europe : Etude du Registre Européen de Transplantation (ELTR) sur 2409 patients. - 15 années d'évolution des résultats de la transplantation hépatique en Europe.