



NEWS

-Editorial-

Dear colleagues and friends,

It is my privilege to present you this special 22nd issue of DA News. I'm sure none of the founding mothers and fathers who launched the Donor Action initiative in 1994 in Sevilla, Spain, would have expected their 'baby' to reach the age of an adolescent: the project they started got founded formally in 1998 as a Foundation under Dutch law, hence this special issue on the occasion of DAF's 15th anniversary.

For us, this seems the right time to look back on how it all started, with a contribution from the Foundation's first Manager, Mrs. **Celia Wight** who will confide you her experience as first European transplant coordinator, and her first project with Eurotransplant's **European Hospital Education Program (EDHEP)** which evolved soon into the **Donor Action** project as from 1994 on.



In this lustrum issue, we will bring you several testimonies of DA users who implemented the DA Program in their country as a quality assurance tool on a national scale, years ago: Dr. **Jonathan Cohen**, national DA Manager in **Israel**, reports on his experience with the Program and how he developed it as a quality assurance tool in all donor hospitals in Israel.

We have two contributions from **Switzerland**, a country that implemented the DA Program locally and many years ago, with reports from **Caroline Spaight**, Swiss national DA Manager, and her colleague **Diane Moretti** who's heading the the Swiss Latin Organ Donation Programme (LODP).

Dr. **Karim Laouabdia** and his colleagues from the Agence de la Biomédecine (**France**) describe their experience with the Program and how it inspired them to incorporate it into France's new Cristal Action program .

Finally, we give you an update on the status of the **DA System Database**, irrefutably the largest database of its kind in the world. Just a few days ago, the Eurotransplant International Foundation's Board of Directors decided to continue hosting and maintaining this database.

Wishing you much reading pleasure and a relaxing summer holiday!

Leo Roels
DA Management



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DONOR ACTION® SYSTEM DATABASE NEWS

“... definitely the largest database of its kind ...”

For those DA News readers who aren't yet familiar with Donor Action's System Database: this is a web-based relational database system used to enter, analyze and report on **Hospital Attitude Survey (HAS)** and **Medical Record Review (MRR)** data and is part of the **DA Diagnostic Review® methodology**. User friendly and designed to detect input errors, the System guides the user through the correct pathways (heart-beating, non-heart-beating and/or tissue donation) to guarantee accurate and consistent reporting. A built-in, comprehensive eLearning tool introduces novice users into using the System. The DA System Database can produce a wide range of pre-set or customized reports, charts, single and cross-type reporting features that form the basis for the unit diagnosis. Data can also be exported as MS Excel files for further analysis by other statistical tools such as SAS and SPSS. It is available in several European languages and also provides an online Translation Module for users who want to translate the whole System into their own language.

With data collected from over 20 countries worldwide, this DA System Database is definitely the largest of its kind: from its start in

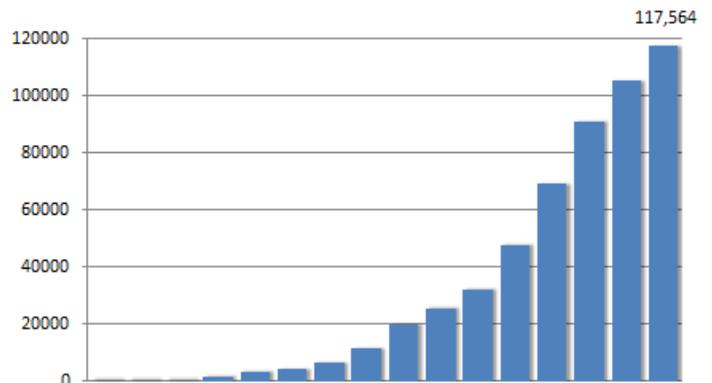


Fig. 1: Cumulative number of medical records entered into DA Database (1996-2011)

peer-reviewed journals (*see: www.donoraction.org > further reading > publications*). A unique achievement, again, thanks to hundreds of users in hundreds of hospitals who collected and entered their data into the Database.

Since 2008, the DA System Database has been hosted and maintained by the IT staff of the **Eurotransplant International Foundation (ETI)** (*Leiden, The Netherlands*). Management is proud to inform our users and DA News readers that the Board of Directors of ETI has decided during its most recent Board meeting to renew its contract agreement with the Donor Action Foundation and continue hosting and maintaining the DA System Database as from 17 December 2012 on. Management would like to thank ETI, its IT staff and its Director Dr. Arie Oosterlee in particular for their generous hospitality in previous years, and is looking forward to continue this collaboration in the years to come. (LR)

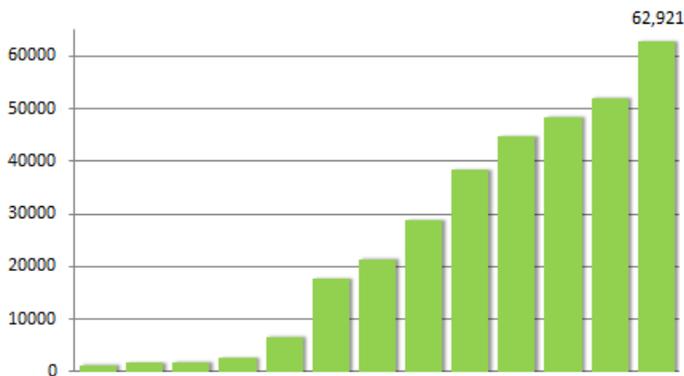


Fig. 2: Cumulative number of HAS records entered into DA Database (1996-2011)

1996 and until the end of last year, **117,564 MRR records** and **62,921 HAS records** were entered into the Database (*see figures*). This wealth of information, collected over the last 15 years, has resulted in over one hundred publications by our users and management in

“... over 100 publications in peer-reviewed journals ...”



Invited paper

MEMOIRS OF A COMMON SENSE APPROACH TO ORGAN DONATION

“One thing we never foresaw in the early days of human kidney transplantation was a shortage of human donor organs.” Sir Roy Calne. Hunterian Lecture, Royal College of Surgeons of England, 1989, London, UK.

Introduction

I wonder which God was looking after me that day in 1979 when I bumped into **Professor Roy Calne** in the car park at Addenbrookes' Hospital in Cambridge, UK? We had not met for over a year and within a couple of minutes I had agreed to be interviewed for a new job, although I had no idea what was involved, that is how I became a transplant coordinator (TC). I was given unprecedented freedom and support by Sir Roy and the Regional Medical Officer and in 1980 started my first tentative steps along a road that took me on my professional adventure around the world. My years as a TC in Cambridge are a story for another time. The main lessons I took from those years were how to deal with large doses of medical condescension, a decreasingly limited pool of suitable human donors and an overwhelming need to professionalize the donation process and isolate it from it from transplant programs. It all seemed so simple to me – just common sense – I never anticipated the walls of resistance that I would meet along the way, often stemming from the self-interests of the transplant community itself.

EDHEP

In 1990, researchers attached to the **Eurotransplant International Foundation** (ET), based in Leiden, The Netherlands, identified multiple reasons for a fall in potential donors within the ET countries (a population of over 110 million people at that time). Importantly, they discovered that many hospitals had no protocols or procedures for organ donation and around 30% of potential donors were lost because of refusal by the family, mainly due to a lack of communication between doctors and relatives of a potential donor.

With funding from The Dutch Kidney and Heart Foundations and Sandoz Pharma (the later Novartis), ET began the development of a communication skills workshop aiming to decrease refusal rates called the **European Donor Hospital Education Programme** (EDHEP), rather a misnomer as it only dealt with one aspect of the donation pathway the “consent process”. A Dutch version was piloted in The Netherlands and in 1992, the final professional education tool was made available to other countries. I was the lucky individual appointed by ET to coordinate the international introduction of EDHEP, under the supervision of **Bernard Cohen**, Director of ET; I was

again given much support and freedom to carry out the task in hand. EDHEP became an international success but what is often forgotten is its unique methodology. The workshop was not a “for sale and leave you to it” item: the philosophy behind the international development was a **“Train the Trainers”** approach, providing training to national stake-holders, tools and continuing support allowing individual countries to modify the contents of the workshop to meet their own national circumstances. It also required “buy in” from departments of health (DOH), organ exchange organizations (OEO) and the directors of critical care units (CCU). Many accolades go to **Jan van Dalen** and **Geke Blok**, for their skills in developing the workshop and training trainers in many countries around the world. The overwhelming impression I am left with following my international experiences with EDHEP is no matter our color or creed, human emotions, in the particular context of loss, grief and organ donation, are essentially the same.

Donor Action®

With the success of EDHEP, it was an obvious next step to evaluate all aspects of the donation process and maybe create a tool to help and support the professionalization of donation within the CCU. The first meeting to discuss this idea was held in 1994 in Seville, Spain, again, sponsored by Sandoz/Novartis. Representatives from Spain (**ONT**), where a unique national network and training courses for donor coordinators were well established, the USA where the **Partnership for Organ Donation** (PfOD) had developed a methodology through medical record reviews (MRR) and hospital attitude surveys (HAS) to “identify” strengths and weaknesses in individual CCUs donation practices. The third partner was **ET**, who had developed EDHEP and the TTT approach. The hope was that these organizations would come together to pool their expertise in an international collaboration using the TTT methodology. This was the first hurdle to overcome. PfOD charged hospitals for its services, and supervised all MRR and HAS, ONT charged a substantial sum for its international training courses. If the ET / TTT philosophy of providing the program at virtually no cost was to be followed, these groups had to be prepared to “give” their expertise to this international initiative. Agreement was reached that pilot MRR and HAS reviews would be undertaken in

four countries: The Netherlands, UK, Spain and Canada. Initially named the Seville Project, it was mainly concerned at this point in identifying when and where potential organ donors were lost. Facilitated by Rowland Healthcare based in Switzerland it took nearly two years to prepare a pilotable draft, and the MRR and HAS studies were started in late 1995. The working group oversaw these pilot studies agreeing that the collection of the data would be left to the individual CCUs to ensure their input and sense of ownership into the project. The pilot studies proved to be a fascinating reflection of human behavior. In the UK, the MRR and pilot hospitals were targeted negatively by several TCs from other parts of the country, claiming that they already had “similar” initiatives in place or they did not want to work with a program funded by Pharma (although many received their salaries from similar routes). Also, the thought of a national approach to organ donation was anathema. In Spain, the MRR data was collected in the pilot hospitals but not according to the agreed MRR formula, all these data had to be re-evaluated. The PfOD supervised the pilot studies in Canada and followed their usual practice by collecting the data themselves, instead of leaving it to the CCUs as intended. Even in The Netherlands, who had already experienced pilot evaluations with EDHEP, all was not smooth going as many uninformed TCs vented against the principles addressed and thought it was all too much work anyway. These were difficult times for us who took a broader view of organ donation but all these concerns had to be navigated. It was all such a long time ago and all the fears of those who felt so threatened by this program have proved to be unfounded – after all, it was only common sense.

Eventually a donation pathway was prepared, a computer database built which analyzed the pilot data and independent international experts validated the methodologies. The pilot studies demonstrated many gaps in the donation process in all CCUs, resulting in the development of modules, with tools for CCU staff to use as corrective measures. The main and very gratifying surprise to me was the overwhelmingly positive response from the critical care community. Once they had had an opportunity to scrutinize the diagnostic phase of this program, in particular the MRR and understood that the ownership and opportunity to improve donation practices where necessary was under their own control, true and lasting partnerships developed.

This historical review would not be complete without acknowledging just some of the individuals whose contributions made **Donor Action** (DA) such a success.

The final name for the program caused the working group some difficulties; the male members immediately vetoed anything associated with “feminine products”, wanting something sharp and snappy – it took us some time and much hilarity to come up with **Donor Action!** I think it came from Novartis’ Les Sharman.

A debt of gratitude is owed to **Genny Deblander** and her team at **Rowland Healthcare**, in particular **Han Wingate** and **Helen Stevenson-Schmidt** for their meticulous eye to details when

scripting the DA materials. Helen’s constant presence and support in navigating the endless difficulties, which cropped up during the pilot studies was invaluable. Eventually, Genny became my constant companion as we ran TTT courses around the world, her expertise was also invaluable as we developed these courses and passed the program onto other countries. Following the registration of DA in 1998 “hands on” involvement from ONT, ET and PfOD began to fade as they undertook an advisory role.

The computer database into which the MRR and HAS data was entered turned out to be the most important tool in the program. We owe an enormous debt of gratitude to **Jacques Martin**, from RM Management in France who spent years with me in developing the database to analyze the results of the ever improving MRR and HAS. Jacques’ patience was endless and we felt an enormous sense of responsibility in holding this database and huge anxiety less any data should be lost, especially, as I had the responsibility of entering all pilot data for analysis into the database.

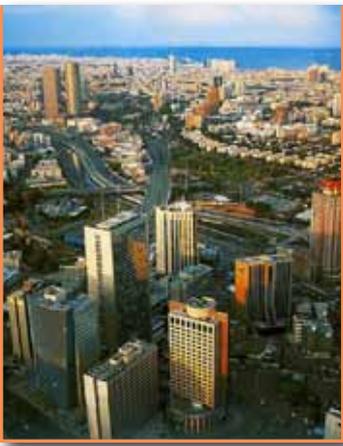
A very important asset was the appointment of **Leo Roels** as assistant manager in 1999. His knowledge, help and support was incalculable to the product, DA. How privileged I am to have had the opportunity to work with all these people and the amazing medical teams I met around the world? It is a truly international collaboration.

Just before my retirement, I saw the DA computer database become web-based and now the largest database of its kind in the world. All accolades for this should go to my colleague and successor Leo Roels.

“... an overwhelmingly positive response from the critical care community ...”



Celia Wight
Former EDHEP and
Donor Action Manager



DONOR ACTION IN ISRAEL

The organ donation rate in Israel remained low over many years despite intensive efforts of the relevant authorities. In 2003, Israel Transplant took a decision to implement a national program of quality control regarding all aspects of organ donation. The Donor Action platform was considered most suitable for this purpose and a national coordinator was appointed. After undergoing a training course in Brussels with Leo Roels, which was intensive, extensive and absorbing, the program was prepared for implementation in Israel. The main elements of the program, including the MRR and HAS, were translated into Hebrew and by 2004, the program was formally implemented

“... Donor Action has become the generic term for quality assurance in organ donation in Israel ...”

under the auspices of the Ministry of Health. The first year was spent performing a base-line analysis of the situation in Israel, both regarding the donation process (MRR) and attitudes of medical staff to organ donation (HAS). The national coordinator, together with a representative of the Israel Transplant Center, visited all 21 hospitals in Israel. Since many patients who require respiratory support are ventilated outside of the ICU due to a serious shortage of ICU beds, files of all deceased patients in all the hospitals were examined – in total thousands of medical records. The findings of each hospital were conveyed to the relevant hospital administration in a formal meeting which was attended by the hospital director, senior administrative staff, the local transplant coordinator, the head of Israel Transplant and the national coordinator.

The initial findings revealed many problem areas, in particular, that many potential donors were not detected, that many potential donors developed a cardiac arrest before brain death could be detected and that the consent rate remained low. In addition, a relatively small but significant number of medical staff, both nurse and physicians, did not accept brain death as a valid determination of death and had not received formal lectures regarding brain death determination and the medical management of the potential donor.

In answer to these problems, many targeted interventions were instituted, including the appointment of a dedicated ICU physician in all hospitals who would work closely in liaison with the transplant coordinator regarding admission of potential donors to ICU, their management, family approach as well as playing a central role in in-hospital education. The stepwise approach of the system certainly allows for ready identification of problem areas and the institution of targeted intervention.

Some unique elements were introduced into the DA program.

These included:

- 1) A 24-hour help center manned by the national coordinator in order to answer queries regarding brain death declaration, management problems related to the donor and suitability of a particular donor for transplantation in the presence of comorbid conditions, eg infections, malignancy, etc. In a typical year between 250 and 300 calls are received;
- 2) An ongoing external audit performed by the national coordinator, where all deceased files are examined using the electronic record systems. All hospitals are visited at least 1 – 2 per year. This visit also allows the national coordinator to hear and solve local problems. Following the audit, the hospital director receives a report regarding the findings;
- 3) Quality control of donor management, using the following elements: whether donors received therapy according to protocol including use of minirin, methylprednisone, vasopressin, etc. In addition, laboratory tests including serum sodium, serum creatinine and blood glucose levels are used as markers of effective therapy.

Over the years there has been a significant improvement compared to the initial survey and for the past few years, over 95% of all potential donors are detected and managed appropriately. In

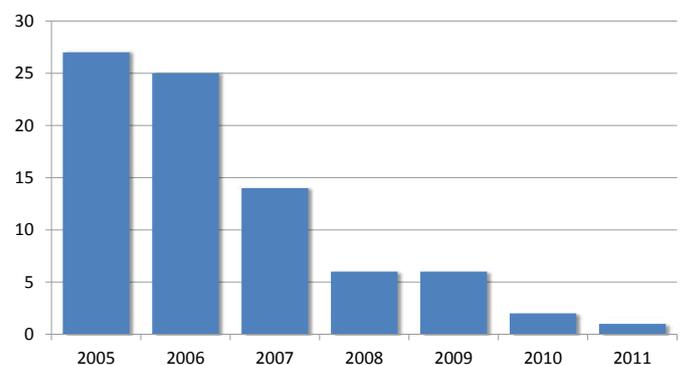


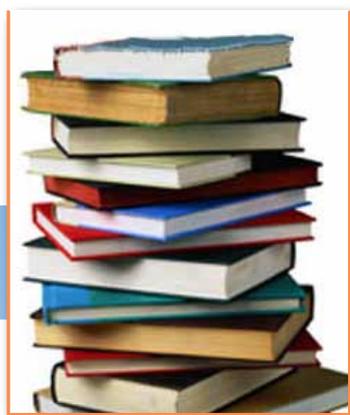
Fig: Non-detected potential donors, 2005-2011

addition, a repeat HAS survey performed in 2009 revealed marked improvement in the attitude to organ donation and brain death by the medical community. There has also been a significant improvement in donor management. The program has achieved wide acceptance and recognition, to the extent that Donor Action has become the generic term for quality assurance in Israel.

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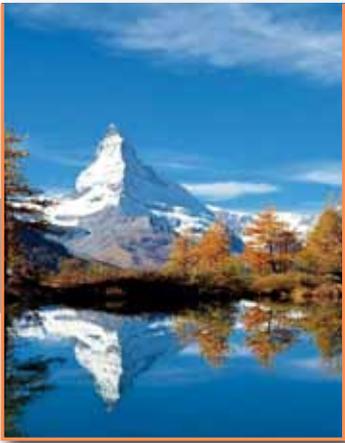
Jonathan Cohen, MD
Associate Professor of
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Medical Advisor, Israel Transplant



RECENT PUBLICATIONS

Since last DA News issue (Summer 2011), yet another few papers on DA activities have been published or submitted for publication in peer-reviewed journals. This totals the number of publications by our users and management currently to 105 papers (for a total list of publications on the experience with the DA Program, please visit our website www.donoraction.org > Further reading > Original articles).

1. **Reasons for not formally diagnosing potential donors brain dead: Donor Action@ Medical Record Review data from 7 countries.**
Roels L, Smits J, Cohen B. *Transpl Int* 2011; (Suppl 2) 78-79
2. **Age as a determinant of potential donor conversion rates: Donor Action@ Database findings.**
Roels L, Lombaerts R, Smits J, Cohen B. *Transpl Int* 2011; (Suppl 2) 79
3. **Cost-benefit estimation of cadaveric kidney transplantation: the case of a developing country.**
Dominguez J, Harrison R, Atal R. *Transplant Proc* 2011; 43(6):2300-2304
4. **Donor Action Program in the Emilia-Romagna Region (ERR): Results.**
De Cillia C, Bonanno MC, Campione T, Ridolfi L. *Transplant Int* 2011; 24(S2):332
5. **The Latin Organ Donation Programme (LODP) – Programme Latin de Don d'Organes (PLDO): An Effective Regional Initiative to Increase Organ Donation in Switzerland.**
Moretti D, Heidegger C-P, The Latin Organ Donation Programme (LODP). *Organs, Tissues & Cells* 2012, 15(1):47-54
6. **Potential for deceased donation not optimally exploited: Donor Action@ data from 6 countries.**
Roels L, Smits J, Cohen B. *Transplantation* 2012 (accepted for publication, 31 July 2012)



15 YEARS SWISS EXPERIENCE WITH DONOR ACTION®

Introduction

Switzerland has a 15 year history with Donor Action corresponding to the international launch of the program in 1997. It was started with a pilot study in the 4 hospitals of the Italian region, Ticino. 15 years later Donor Action has been implemented in 48 hospitals, which include all the University hospitals and has collected over 20'250 Medical Record Reviews and nearly 5'000 Hospital Attitude Surveys.

Switzerland is a country with 7.9 million inhabitants and has three linguistic regions, German, French & Italian. The country has 26 cantons, each responsible for its health laws, directives and application.

There are 73 hospitals within the country that have one or several intensive care units recognized by the Swiss Society of Intensive Care which include 5 University Hospitals and 6 transplant centers, Basel, Bern, Geneva, Lausanne, St Gallen and Zurich.

The Swiss Experience

As the majority of European countries in the late 1990's, Switzerland was looking for initiatives to improve donation. Donor Action appeared to be the ideal program with its package of analytical tools, model procedures and training materials designed for and driven by critical care units.

Despite a successful pilot study in Ticino in 1997, and a positive role out in two University Hospitals from different linguistic regions (Lausanne, French region and Zürich, German region) in 1998, the program did not take off. The principle reasons being, a wrong approach, with the transplant community having been initially involved rather than the ICU community together with a lack of adapted materials of the Donor Action Program. So as to correct these problems, a National Donor Action committee was created in 1999 with ICU physicians from Lausanne, Ticino and Zurich and Transplant Coordinators from Lausanne & Zurich so as to introduce and support participating hospitals with representatives in the three linguistic regions.

The Swiss National Committee created two European working

groups, a French one with l'Etablissement Français des Greffes, today known as Agence de la Biomédecine and a German group with the Deutsche Stiftung Organtransplantation to bring together expertise and facilitate the translation of the Donor Action materials. Each country adapted its materials to its local legislation.

With this new approach the number of participating hospitals had doubled the following year which led the National Committee to create a more formal and independent structure to promote, support and develop the Program. The Swiss Foundation to Support Organ Donation (FSOD) was established in the year 2000 as the first organization in Switzerland devoted solely to donation. It was ICU based and supported by the Swiss Society of Intensive Care, SwissTransplant & the Federal Office of Public Health.

What did Donor Action show & what actions did we take?

Switzerland chose to use the Diagnostic Review of the Donor Action Program, the Medical Records Review (MRR) & Hospital Attitude Survey (HAS). Participation was on a voluntary basis. We took many years before showing our results, principally as we are a small country with a high concentration of hospitals with very small study samples. However, between 1999 and 2005, analysis of data repeatedly showed weaknesses in the donation process.

The MRR showed two important factors; 1) that we were losing over 30% of our pool of potential donors; that is to say patients with suspected or formal criteria for brain death diagnosis. Although the reasons for the loss were multifactorial, 50% of these losses were due to management failures. 2) the absence of tissue donation activity.

“... a steady increase in donation rates from 17 donors pmp in 1997 to 43 pmp within a couple of years (Ticino area) ...”

The HAS showed a lack of knowledge of the local situation, including existing protocols, guidelines and practices in

Switzerland; staff knowledge & skills were below average in donation related issues, with an important request for education.

Three important targeted actions were implemented:

- 1) FSOD's first project in 2001 was the development of a National Educational Program on the organ donation process; a series of courses, modular based, to cover theoretical & practical aspects of the organ donation process which could be offered to all hospitals whether they were using the Donor Action Diagnostic

review or not. A project manager was appointed.

- 2) The development of a "Swiss Donation Pathway" in January 2005 for heart-beating donors based on the Donor Action steps.
 - a. Donor Identification & Referral
 - b. Family Care & Communication
 - c. Donor Maintenance
 - d. Donor Retrieval
 - e. Effective Communication for hospital staff

The FSOD decided to create a series of national guidelines & protocols of the donation process but chose to develop its own pathway due to the specifications of a new Federal Law which were to be implemented in 2007. The first module, Donor Maintenance; "Guidelines for the treatment and monitoring of adult heart-beating donors" was launched in 2006 and distributed to all ICU's in the country. There was an immediate impact in the loss of potential donors due to management failures, which is less than 5% today.

- 3) The development of a project for Corneal Donation in 2006. This was developed and piloted at the University Hospital in Lausanne in conjunction with the eye bank following approval from the Cantonal Health Authority. This was implemented as an institutional directive where hospital deaths are systematically referred for corneal donation.

As from 2006 it was decided that the Diagnostic Review should be implemented to the maximum number of hospitals to monitor the potential for donation on a national scale. All hospitals from the French and Italian linguistic region chose to adhere together with all the hospitals in and around the Zurich area. All the University hospitals were involved. This major role out was conducted between 2007 and 2008.

Results: The Ticino area had a steady increase in donation rates from 17 donors pmp in 1997 to 43 donors pmp within a couple of years, a donation rate which has been maintained to this day. This region, with the particularity that it is entirely driven by the ICU community as there are no transplant services, has constantly implemented improvement measures and monitored the impact of its actions, adjusting where it is required.

For the rest of Switzerland although we have been using the Diagnostic Review for many years, little data has been published. The FSOD who identified a number of weaknesses, and a large variations in donation rates by linguistic region could only offer limited generalized actions due to lack of resources. Hospitals participating on a voluntary basis had no obligation to implement any improvement measures before the introduction of the Federal Law on transplantation. Two regions, the French & Italian linguistic area chose to implement change based on their results, today these regions have fused to become a network, the LOPD, The Latin Organ Donation Program. A detail of their experience is given in this newsletter.

Conclusion: With the implementation of the new Federal Law in July 2007, a number of important changes occurred.

In 2009 the FSOD handed over its activities to the Comité National

pour le Don d'Organes (CNDO), a new committee which was created by Swisstransplant specifically for donation activities. It is principally ICU driven.

The CNDO received a mandate to conduct a national study to determine why Donor Action data show important differences in organ donation rates between catchment areas in Switzerland. For this reason a Swiss tool has been developed, Swiss Monitoring of Potential Donors (SwissPOD) with a special emphasis on problem areas identified with Donor Action. The study was accepted and is actually running in 100% of Swiss hospitals. The study period started on 1st September 2011 and will end on 31st August 2012. This Swiss

study has actually replaced Donor Action. It was necessary for Switzerland to develop its own tool to comply with the Swiss Federal Transplantation law. However, the Donor

Action diagnostic review has shown to be an efficient tool to identify how many, where and why potential donors are missed.

"... DA Diagnostic Review: an efficient tool to identify how many, where and why potential donors are missed ..."

Acknowledgments

I would like to take the opportunity to thank all the hospital staff of the 48 hospitals who have been involved in collecting and entering data for donor action over all these years as well as the health care professionals implicated with the donation process. Equally I wish to address special thanks to the physicians who spent a lot of time and effort on a voluntary basis to develop a national team devoted solely to organ donation before the logical handover of activities to Swisstransplant.

Past FSOD presidents:

Dr. H. Brunner, Prof. R. Chioleró, Prof. S. Martinoli, Prof. R. Stocker, Prof. P. Suter, Prof. Th. Zeltner, Prof. R. Zinkernagel

Past FSOD executive managers: Mrs G. Eschenmoser, Mrs C. Spaight- Gachet

Past Board members: Dr. M. Betschart, Dr. Ph. Eckert, Dr. A. Frutiger, Dr. O. Gehrig, Dr. E. Giostra, Dr. Ch. Habberthür, Dr. Ch. Jäggi,

Dr. M. Kiess, Prof. R. Malacrida, Prof. S. Marsch, Mrs P. Pesenti,

Dr. Ch. Rouden, Mrs P. Seeburger, Mr. P. Urech, Dr. Th. Weber, Past members: Mrs. P. Bischoff, Mrs. A. Bocchi Mrs N. Bodri, Mrs. N. Böhmer, Mr. M. Blum, Mr L. Imperatori, Mrs. D. Moretti, Mrs. M. Perruchoud, Mrs U. Schäfer, Mrs M. Strucker, Mrs. I. Van Hollebecke, Mr. Th. Vogeles, R. Wullschlegler



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THE LATIN ORGAN DONATION PROGRAMME (LOPD) PROGRAMME LATIN DE DON D'ORGANES (PLDO)

The 1st Swiss federal Transplant Law of 2004 was finally enforced in July 2007 with the obligation to promote quality and efficiency in the procedures for organ and tissue donation for transplantation. The average annual Swiss donation rates have stagnated around 12 donors per million of population since 2002 and are amongst the lowest in Europe. The Latin Organ Donation Programme (LODP) was created in 2008 with the aim to develop organ donation in an area covering 2.2 million people; 29% of the Swiss population, concerning 7 Latin (French and Italian speaking) cantons and containing 17 public hospitals.

With the creation of LODP, the Latin provinces allotted a budget to fund the positions of Local Donor Coordinators (LDCs) in the public hospitals and also for the central structure. The start-up date of the LODP was the 1st of July 2008. Our aim is to optimise the identification and management of organ donors and to ensure that organ and tissue recovery takes place in a respectful manner in all of the partner hospitals. The LODP has 17 network partners; ten hospitals which can identify and transfer potential donors to reference centres plus seven hospitals which can organise in-house procurement, including four with a neurosurgery department and two university procurement-transplant centres. Each hospital has designated at least one LDC (nurse or physician), member of the intensive care team. Their training was completed in spring 2009 and combined with other measures; such as the transfer of Transplant Procurement Coordinators (TPCs) to the outlying hospitals for organ recovery, the start-up of the hotline and the activation of the web-site, the LODP was fully functional by the second part of 2009.

The LDCs are in close contact with the central structure of the LODP and in particular with the General Coordinator, whose role is to organise training sessions, give support and find solutions to problems as well as supplying documentation to the partner hospitals (procedures, courses, etc.). The missions of the LDCs are mainly: the development and distribution of procedures related to organ and tissue donation and the introduction of a quality control programme (Donor Action) in this area, together with training and information of the medical-nursing staff, especially in acute hospital areas (emergency room, ICU, anaesthesia, operating room) involved in organ & tissue donation.

The university hospitals of Geneva and Lausanne employ TPCs since the 1990's and outlying hospitals which can provide in house organ recovery can request the transfer of a TPC to attend the coordination process and organ recovery as required. This service is greatly appreciated by the teams involved. In addition a hotline has been established to help doctors faced with legal, medical or logistical issues regarding the donation process.

We have been using Donor Action since 1999 in a small number of our hospitals and it was introduced into all 17 of our partner hospitals in 2008. The Hospital Attitude Survey (HAS) has also been carried in most of the LODP hospitals; 2835 questionnaires were distributed to health care professionals in acute hospital areas (emergency room, ICU, anaesthesia, operating room) involved in organ & tissue donation. The LDCs were specifically trained in the organ donation process with a special emphasis on the implementation of protocols and the organisation of training sessions for hospital staff. They have also been trained to carrying out parts of the Donor Action® programme. This tool has provided us with a baseline enabling us to identify the needs and performance of the staff in the different hospitals. A feedback of the findings has been given to the staff concerned and the individual hospital medical directors. The most frequent topic requested in the HAS was communication with the relatives and seeking consent for donation. Consequently, we now organise one day seminars for health professionals concerning bereavement and organ donation, which contain clear steps about how to approach relatives, breaking bad news and seeking consent for donation, we also address the theoretic and practical issues surrounding donation.

Results of the Hospital Attitude Survey

When the health care professionals were asked about their attitude: 85% doctors would give their organs and 81% their tissues, 81% nurses would give their organs and 76% their tissues. 78% of other staff would give their organs and 71% their tissues. When asked if brain death is a definition of death, 16 % replied negatively, citing three main reasons; insufficient information about brain death (3%); doubts about the scientific definition (6%); religious beliefs and personal values (7%). In conclusion, 90% of health care professionals support organ donation in general; 30% have been implicated in the process and 55% requested specific training in the organ donation process.

Results of the Medical Record Review

Using the DA reporting feature, we analysed 4920 records of patients who died in Adult ICUs in the LODP region, using retrospective data collected with the Medical Record Review (MRR) form, between January 2007 and December 2011. Over the five year period the average annual number of deaths in ICU was 984 and the number of medically suitable patients with cerebral lesions averaged 235 with a peak of 266 in 2010 leading to the highest number of eligible donors 79 compared with an average 59. Consent rates varied between 74 % in 2009 to 49% in 2011, with an average of 64%. The utilised donor numbers rose rapidly from 32->30->43->51, this unfortunately was

not sustained in 2011 with a drop to 26 utilised donors. The number of organs procured per donor increased from 3.75

to 4.01, which is amongst the highest in Europe.

During 2011, all conversion rates dropped significantly compared with 2010, previously the percentage of utilised donors versus all deaths had risen from 3.3% in 2007 to 5.2% in 2010, then halved in 2011 to 2.6. The results for 2011 are provisional and a slight difference can be expected but what emerges is that with such small numbers, variations in potential donor numbers have a dramatic effect on the number of utilised donors. We need to maintain the conversion rates obtained in 2010 and we have a clear objective to improve consent rates but without putting pressure on next of kin.

NB: In addition to the 26 utilised donors, there was one effective donor (organs procured but not transplanted) and 2 child donors who are not included in this study as Donor Action was not running in paediatric ICU's at during time.

We believe that the introduction of Donor Action into the LODP combined with the motivation of the LDCs who carry out the MRR has contributed to an increased level of awareness of ICU medical staff about organ donation.

Experts in the field of organ and tissue donation have been working together to create regional and national recommendations and protocols, some of which are already available on the LODP web-site (www.pldo.ch). For example; the brain death protocol, management of potential donors, information and support for relatives, coordination process, as well as donor care in anaesthesia and organ recovery. A detailed training programme has been made available to the partner hospitals with a complete set of didactic materials also available on the LODP web-site. The implementation of the transfer

“... the introduction of DA ... contributed to an increased level of awareness of ICU medical staff about organ donation ...”

of TPCs for organ procurements to the partner hospitals was a successful innovation. The LODP has proved that

putting into place efficient measures relating to the organ donation process has been beneficial and the collaboration between the ICU staff, the LDCs and the General Coordinator of the LODP is primordial in this success.

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FROM DONOR ACTION TO CRISTAL ACTION, THE FRENCH EXPERIENCE

A program aiming to improve organ donation and procurement in every hospital has always been one of the main objectives of the Agence de la biomédecine which oversees organ donation, procurement and allocation in France.

The Donor Action (DA) project was born of the determination of a group of international pioneers; it was made available to transplant coordinators in France as of 2002, and a national steering committee, supported by the international board of DA, was established (the

project manager was Bernard Loty who has been replaced by Daniel Maroudy). We must thank the committee for its continuous support and all the transplant coordinators who boldly took the decision to implement Donor Action in their centres.

The first hospital to start DA was Perpignan in 2002 followed by Chalons/Saone, Caen and Rouen. In 2008, 46 out of 157 hospitals authorised for organ and tissue procurement had data. This was achieved thanks to training courses dispensed to 120 doctors and

190 nurses and the invaluable help of a hotline.

Although the programme needed a CD and installing the software was quite difficult at the beginning, this was not enough to stop the enthusiasm of those involved in the programme who knew its advantages.

In the majority of hospitals where DA was installed, the average number of harvested donors increased by 30%. This effect was particularly noticeable in the first year of implementation, but has subsequently stabilized.

Donor Action has shown that:

- Organ donation was sometimes not considered during the management of critical patients.
- Organ donation procedure began before brain death diagnosis in emergency units.
- Benchmarking between hospitals was not straightforward.
- Implementation of the programme was in itself sufficient to increase organ donation.
- It was possible to raise awareness within hospitals by using questionnaires about organ procurement.

“... implementation of the program was in itself sufficient to increase organ donation ...”

in 2008, an evaluation confirmed that using Donor Action was the right strategy. It was a new and an innovative approach to assess the potential of local organ donation and, to a certain extent, the simplest and the most effective method.

However, it became obvious, over time, that assessing the potential of donors at a national level was a challenge that had to be overcome. To do it, a better understanding of the actual number of deaths due to a brain injury was needed. Moreover the heterogeneity found in organ procurement rates between regions in France was not easy to explain and basic indicators were not able to explain the differences. What was required was a real understanding of possible and potential donors as referred in the DOPKI project (1).

The utilisation of Donor Action as a tool to increase organ procurement was clearly mentioned during the debates held when preparing the revision of the bioethical law

Spreading the DA “attitude” was then set as a priority. For this purpose we needed to:

- Involve a greater number of hospitals.
- Adapt our approach in training and supporting transplant coordinator teams so that they could promote and implement the programme more efficiently.
- Include updated recommendations regarding extended criteria donors, next of kin interviews, even in the context of withholding

or withdrawing support therapy (2).

- Monitor the transfer of donors from the emergency unit to the intensive care unit within an effective organ procurement network.

Unfortunately, with time, several teams stopped collecting data, improvement plans were poorly implemented and the program gradually stopped

We therefore decided to make the programme evolve. A new software was designed (Cristal Action) and we changed the way the implementation of the programme was organised.

At that time, we had a database with an on-line system for organ donation and a recipient waiting list (Cristal) for transplant allocation. Only brain dead donors were

entered in the database, whether donation took place or not. We then extended this process to potential donors, with improved descriptions of next of kin interviews and donor management. A powerful statistical tool, Microsoft Excel compatible with predetermined modifiable requests, was included in our Cristal software.

With regards to the organisation, each region was made responsible for the implementation of its programme with the obligation to report to a national steering committee.

But the most important decision was to focus on quality management. Our programme Cristal Action (3), aims to improve processes continuously in accordance with the certification of transplant coordination.

To be effective, Cristal Action requires a real ownership by every transplant coordinator.

To conclude, Donor Action has given us a model to increase the number of potential donors by strengthening the role of transplant coordinators and assessing the practices of medical teams.

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UPCOMING EVENTS

August 12-15, 2012

NATCO 37th Annual Meeting

Grand Hyatt Washington

Info: www.natco1.org/education/annual-meeting.asp

October 5-7, 2012

2012 European Organ Donation Congress "Science needs a heart";

24th ETCO-EDC

Dubrovnik, Croatia

Info: www.esot.org

October 11-12, 2012

Eurotransplant Annual Meeting 2012

Leiden, The Netherlands

Info: mfranzen@eurotransplant.org

October 12-14, 2012

ESOT and AST Joint Meeting

Nice, France

Info: www.esot.org

October 13-17, 2012

European Society of Intensive Care Medicine 25th Annual Congress

Lisbon, Portugal

Info: www.esicm.org

October 21 - 23, 2012

International Transplant Nurses Society, 2012 Annual Symposium

Seattle, WA, USA

Info: www.itns.org

November 2-5, 2012

NATCO Donation and Transplantation Academy:

A Multidisciplinary Approach

Tempe Mission Palms, Tempe, AZ, USA

Info: www.natco1.org/education/donationtransplantationacademy.asp

November 21-23, 2012

21st Annual Congress of the European Association of Tissue Banks (EATB 2012)

Vienna, Austria

Info: www.eatb2012.eu

February 1-3, 2013

NATCO 2013 Symposium for Advanced Transplant Professionals

Loews Miami Beach Hotel, Miami, FL, USA

Info: www.natco1.org/education/satp.asp

April 20-24, 2013

3rd Ethical, Legal and Psychosocial Aspects of Organ Transplantation (ELPAT) Congress

Rotterdam, The Netherlands

Info: www.esot.org

April 24-27, 2013

33rd Annual Meeting of the International Society for Heart & Lung Transplantation (ISHLT)

Montreal, Canada

Info: www.isHLT.org

August 11-14, 2013

NATCO 38th Annual Meeting

Manchester Grand Hyatt, San Diego, CA, USA

Info: www.natco1.org

September 3-6, 2013

13th Congress of the Asian Society of Transplantation

Kyoto, Japan

Info: www.congre.co.jp/cast2013/

November 21-24, 2013

2013 Organ Donation Congress (ISODP 2013)

Sydney, Australia

Info: www.isodp2013.org

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