Submission No 16
Spec Inq

AUSTRALIANS DONATE

Australia's National Organ and Tissue Donation and Transplantation Network

Chairman: His Excellency Sir Eric Neal AC CVO, Governor of South Australia

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9th June 1999

Mr Gary Fenlon MLA
Chair, Legal, Constitutional & Administrative Review Committee
Parliament House
BRISBANE QLD 4000

Dear Mr Fenlon

RE: INQUIRY INTO THE TRANSPLANTATION AND ANATOMY AMENDMENT BILL 1998

We thank you for your invitation to make a submission to your Committee on this matter. We were also most grateful for the opportunity to meet with you and discuss national efforts to lift organ/tissue donation rates. The attached submission, as then discussed, addresses the terms of reference of your Committee's Inquiry - viz it responds to the Private Member's Bill which generated the Inquiry, then offers for your Committee's consideration a number of recommended actions, which from the experience of our National Network we believe should be considered in any effort to lift Queensland's donation rate.

While we cannot support the tenets of the Bill, for reasons outlined in the attached submission, we applaud the Member for Thuringowa for bringing this matter to the attention of the Parliament, and raising for discussion the community value of organ/tissue donation and transplantation. If your Committee can, as a result of the referral of the Bill for its consideration, now make some clear recommendations for actions to address problems which are responsible for Queensland's less-than-optimal donation rate, then the introduction of this Bill will have achieved much of value.

This submission is lodged by the National Director of Australians Donate, Mr Bruce Lindsay, in association with the Member of National Council, Professor Geoffrey Dahlenburg, who is formally authorised by the Council to make public statements on behalf of the organisation. Time-limits have not allowed this submission to be formally endorsed by a meeting of the National Council, but the writers undersigned have no reason to believe that the contents of this submission would be other than endorsed by the Council.

Please would you accept this submission as being also representative of the views of the South Australian Organ Donation Agency, which is in agreement with its contents

Yours sincerely

PROFESSOR GEOFFREY DAHLENBURG
Member, National Council, Australians Donate
Director, SA Organ Donation Agency

BRUCE LINDSAY
National Director, Australians Donate

Generously supported by Australian Commonwealth, State and Territory Governments, and

JANSSEN-CILAG IMMUNOLOGY AND TRANSPLANTATION
NOVARTIS
Roche Transplantation

SUBMISSION TO THE LEGAL, CONSTITUTIONAL AND ADMINISTRATIVE REVIEW COMMITTEE
of
THE LEGISLATIVE ASSEMBLY OF QUEENSLAND
re
INQUIRY INTO THE TRANSPLANTATION AND ANATOMY AMENDMENT BILL 1998

Background to this submission

This submission is presented on behalf of Australians Donate, Australia's national organ and tissue donation and transplantation network, and the South Australian Organ Donation Agency (SAODA). The national network comprises more than 160 agencies and units covering all States and Territories, involved directly in donation and transplantation activities.

The various categories of activity are each represented by members on the governing National Council of Australians Donate, comprising 25 Members. ***A list of Members and the agencies which they represent is found at Attachment 1. A copy of the Annual Report of SAODA for 1998, detailing its structure and activities, is appended at Attachment 2.***

Unlike its predecessor national organisation, ACCORD, Australians Donate operates under a charter which gives precedence to a single goal; to remove any remaining impediments to the achievement nationally of what is deemed to be the optimal organ/tissue donation rate.

The Secretariat of Australians Donate has for some time been aware of the Bill in question, and prior to its referral to this Committee for its consideration, a letter outlining some possible areas of action with respect to annotation of licences with drivers' donor status was forwarded to the Queensland Minister for Health, Hon Wendy Edmond MLA. ***A copy of that letter is appended at Attachment 3***

Australians Donate and SAODA encourage the Committee to explore and recommend upon ways in which impediments to achieving optimal donation rates in Queensland may be removed, and offer to assist by way of further contact and/or submissions on particular issues. We wish the Committee well in its deliberations on this matter of enormous community value.

For the purposes of this submission, our principal interest is the donation rate for "solid organs" - viz hearts/lungs/livers/pancreas/kidneys - rather than tissue such as corneas/heart valves/skin/bone, since supply of tissue from non-heart-beating donors is less emotionally charged than for the heart-beating donations required to ensure maximum viability for transplanted solid organs.

Donation rates for tissues rather than solid organs also currently come very much closer to demand than is the case for solid organs, meaning short waiting times and, in some cases, reserve supplies.

RESPONSE TO THE BILL

Australians Donate and SAODA applaud the Member for Thuringowa for raising this issue for discussion at Parliamentary level, and we also applaud the wisdom of the Parliament for referring the Bill to this Committee for examination.

From the provisions of the Bill, and the Member's Second Reading Speech, we understand that the Bill seeks to

- give legal status to an indication of positive donor status on a Queensland driver's licence
- by so doing, to permit the removal of human tissue without further authority, following the potential donor's descent into brain death
- deny the donor's family or next-of-kin of the right to veto or amend the potential donor's intention as annotated on their driver's licence, except where they believe that the indication is either incorrect or has been changed.

In his Second Reading Speech supporting his Bill, the Member for Thuringowa is largely correct in the information he has presented to Parliament, but the Committee may care to note the following:

a. since 1965 there have been more than 28,000 transplants performed in Australia, not the 15,000 quoted by the Member;
b. whether or not Australia's donation rate is "the lowest... in the western world" is a matter of interpretation, and does not reflect any unwillingness by Australians to identify themselves as potential or intending donors. ACCORD surveys show that up to 90% of Australians support organ/tissue donation, meaning that impediments to donation are ***not*** issues of public support.
c. we find no evidence to support the Member's quote that "twenty percent of ... patients will die before an organ becomes available". Our figures indicate that, in 1998, the actual number of deaths of patients awaiting solid organ transplantation was 94, while the average number on the waiting list was 1711, which translates to a percentage of 5.5%;
d. while the lift in South Australia's donation rate has indeed been dramatic since the introduction of SAODA, the rise to 23 donors per million of population (pmp) occurred in the third year of its life, and not on the first anniversary of its establishment.

It is however encouraging to note that Queensland has consistently performed better than most States except South Australia. ***This is indicated on the table extracted from the Annual Report of SAODA for 1998, which is found at Attachment 4***

While applauding the intentions of the Member in introducing the Bill, and supporting absolutely his wish to remove impediments to organ/tissue donation in Queensland, Australians Donate and SAODA urge the Committee to not support the Bill. We do so for the following reasons:

- The input of any amount of data is subject to standard error rates, meaning that a "yes" recorded on licence data (as against the licence itself, which in many cases is not accessible to ICU staff) may well be incorrect.
- The Member correctly identifies negative media coverage of organ/tissue donation as being a major determinant of public attitude toward donation. Since in 1998 there was a total of only 40 solid organ donors in Queensland, the creation of any form of adverse public comment by a disaffected donor family may well damage public confidence in the donation process, to a degree out of all proportion to the good intentions of the Bill.
- Donor families can be a powerful positive force in our quest to lift donation rates. We would prefer that the wishes of donor families be respected, even if that means that they retain the right of veto over a donation. It is our responsibility to aim to refine donation processes so that donor families can derive comfort rather than anguish from donation. This has been one of the major successes of SAODA, with the formation of the donor family support group, GIFT.
- The Bill is strongly analagous to the "opting out" procedures used in some European countries, and where donation rates have not been seen to rise consistently following their introduction. "Opting out" means that medically suitable donors are presumed to consent to donation, unless they have otherwise specified; "Opting in" allows the donor and/or the donor's family to elect to donate. Studies of those European countries using the "Opting out" scheme show a variable response in terms of donation rates - the highest rate following its introduction still being an unspectacular 15 donors pmp (close to the rate achieved last year in Queensland - 12 donors pmp, without using the "opting out" procedures).
- Surveys by the former national organisation, ACCORD, show that up to 90% of Australians support the principle of organ/tissue donation, and thus do not require the compulsion introduced by the Bill in order to register their positive interest.

We find ourselves in agreement with the Bill's principal objective - and that is to bring forward the decision to register as an intending donor, rather than leave that weighty decision for the highly stressful and emotional environment of an Intensive Care Unit (ICU), when the donor is approaching "brain death". We are however at odds with the Bill on the subject of how to achieve that objective.

Australians Donate is presently pursuing the concept of a national donor database, accessible to donor coordinators in all States and Territories at the time of a potential donor's death. We intend that such a database should comprise only those details which indicate a positive donor status, but that this information be available - if required - to donor coordinators and ICU staff at the time any decision is taken to request donation of the donor's family.

WE RECOMMEND that

(i) the motion for adoption of the Bill be not agreed to;
(ii) the Queensland Government support the introduction of a national donor database, by way of removing legal and operational obstacles to its introduction and use; and
(iii) the Queensland Government facilitate access to existing driver's licence data relating to donor status, as hereinafter described.

ISSUES IMPACTING UPON ORGAN DONATION RATES IN QUEENSLAND

A. ACCESS TO DRIVER'S LICENCE DATA ON DONOR STATUS

All Australian States except Victoria offer to drivers the option of indicating donor status on their driver's licence; this data is stored additionally on licence authorities' databases. While licence-holders will usually carry their licences with them, in tragic circumstances leading to their admission to a hospital's ICU, almost invariably the ICU's medical staff and donor coordinators do not have access to the patient's personal effects. For this reason, access by such staff to the licensing authorities' databases is a major factor in identifying whether or not this patient has indicated a wish to become a donor in the event of his/her death.

We submit to the Committee that foreknowledge of a patient's donor status can be a strong determinant of whether or not donation proceeds. At the same time we wish to put to rest a common myth about organ/tissue donation. ICU specialists and their staff will always make every effort to save the lives of all patients admitted to their care, regardless of whether or not they have indicated a willingness to donate. There is always a clear separation between the ICU and the transplant teams, the latter having no role in the treatment of any ICU patient, nor being in a position to apply pressure to salvage organs needed for transplantation. Transplant teams do not become activated for a possible transplant until well after the donor has been declared "brain dead", and the nationally-respected and practised organ allocation procedure has concluded where the donated organ(s) should go.

Such foreknowledge offers relief from the uncertainty on the part of ICU staff, donor coordinators and the donor's family about the donor's wishes, meaning that the family is relieved of the responsibility of themselves making a decision on whether or not donation may proceed, at a time of enormous emotional stress. The Committee should not under-estimate the impact of this issue on donation rates. A study in Victoria has indicated that, where a patient's positive donor status is known at the time of declaration of "brain death", in all cases the donor's family consented to donation. Where, however, donor status was not known, refusal rates were 39% of requests.

Since the actual numbers of donations are already small, and are thus swayed dramatically by just a handful of lost or missed donors, 39% of requests lost translates into a number of potential donors who would otherwise have saved many lives, and whose contribution to that State's donation rate would be considerable. For example in 1998, there were 40 donors for the year in Queensland, and a donation rate of 12 donors pmp. Add 39% (in an assumption that there were as many missed donors as occurred in the Victorian study), and the number of donors increases to 55, and the donors pmp donation rate lifts to 16 - comfortably ahead of all States except South Australia, and almost 50% higher than the national donation rate for that year (10.5 donors pmp).

Yet in Queensland the considerable value of driver's licence data, as an indicator of donor status, is largely negated by problems of access to that data. We understand that, while the data is listed on the licence authority's central database, direct access by donor coordinators to the data is denied.

We further understand that this problem of access relates to a Crown Law decision which concluded that release of donor status data, even upon the legal death of the licence-holder, contravenes privacy or confidentiality laws.

While we have not been privy to the wording of that Crown Law decision, we find it difficult to understand how the voluntary marking of a licence, to indicate a wish to donate organs/tissue at the time of death, should be viewed other than the holder's desire for release of that information to help facilitate donation.

WE RECOMMEND THAT

(i) the Committee note the value of release of donor status data from licence-holders to donor coordinators and/or ICU staff, at the time of the declaration of "brain death" of the licence-holder, as an element in lifting donation rates;
(ii) that the Committee act within its powers to recommend such revision of driver's licence management in Queensland, as will permit such release.

The matter of access to databases held by licensing authorities is not unique to Queensland, and in an effort to resolve it and associated issues, the National Director of Australians Donate last year prepared a paper which attempts to outline a model system for the operation of licence annotation systems. ***A copy of that paper is now attached - Attachment 5 - for the Committee's information and use.*** Australians Donate would be pleased to be involved, if required, in further discussions on the matters raised in this paper.

B. QUEENSLAND'S INVOLVEMENT IN A NATIONAL DONOR DATABASE BY WAY OF "NEVDIS".

Closely allied with the above item is the potential for aggregation of donor status data currently held on driver's licence databases in Australia onto a national donor registry. Such a registry would provide all of the abovementioned advantages of relieving the stress of uncertainty about a donor's wishes with respect to donation, but it would operate nationally.

For example, currently if a Queensland resident is interstate and suffers such trauma as reduces him/her to "brain death", there is currently no way in which donor coordinators, ICU staff or the next-of-kin can access the Queensland licensing authority's database to confirm donor status.

Australians Donate has been made aware of a national database named "NEVDIS", an acronym for National Electronic Vehicle and Driver Information System. NEVDIS will effectively place all driver and vehicle data onto one centralised database.

Discussions with its governing Reference Group indicate that, while the value and efficiency of a national donor registry downloading masked donor status data on potential donors is acknowledged, it is likely that Australians Donate would need to negotiate separately with each jurisdiction to secure their permission to have such access.

It is ironic that Queensland enjoys the highest rate of positive donor status indicated on driver's licences, yet the value to be derived from release of that information is currently blocked. ***A copy of the latest survey, by Australians Donate, of donor status as indicated on driver's licences, is appended at Attachment 6.***

WE RECOMMEND THAT

The Committee seek to obtain authorisation from the Queensland driver's licensing authorities for release and periodic downloading of data relating to those licence-holders who have indicated positive donor status on their licences, for the purposes of a national donor registry, on terms and conditions to be negotiated with Australians Donate.

C. CENTRALISING OF DONOR COORDINATION SERVICES

We note and applaud the Queensland Government's creation of a single donation agency under the name "Queenslanders Donate". The experience of the SA Organ Donation Agency indicates that such an agency, separated from the hospital environment, and able to actively promote to the community the value of donation, can have an early and dramatic positive impact upon donation rates.

While we do not presume that the South Australian model may be successfully replicated in its entirety in other jurisdictions, we note that Queenslanders Donate adopts the key elements of

- centralised, staffed and separately and adequately funded agency
- representation of all major players in the State's donation infrastructure
- clear separation of the donation agency from transplant units

We are not aware whether or not Queenslanders Donate will embrace a system of medical donor coordinators within the ICUs of donating hospitals; if not, we warmly recommend that this element be included.

We have concluded that the establishment of clear lines of communication between the medical intensive care specialist who identifies a potential donor (ie a patient who appears to be declining toward "brain death") and donor coordinators is essential, if those preparations necessary to maintain the donor in a state suitable for donation, and to discuss donation with the next-of-kin, are to occur within the tight timeframe allowed for any donated organs/tissue to have the best chance of viability as transplanted material.

We note and applaud the appointment of Ms Tina Cooper as Manager-designate of Queenslanders Donate. Ms Cooper is widely respected nationally for her long service as a donor coordinator, and she will bring to the position a current network of all the major players in organ/tissue donation within Australia, and personal and professional integrity which we are confident will confer immediate credibility upon the new organisation. We look forward to working with Ms Cooper and Queenslanders Donate in the achievement of our shared goals.

D. INTEGRATION OF DONOR IDENTIFICATION, REFERRAL and MANAGEMENT WITHIN HOSPITALS

Already mentioned above is the imperative that there need to exist established and clear channels of communication within hospitals, to minimise the number of "missed" or "lost" donors.

A major component of the identification of potential donors is the identification of how many, and by what means, donors have been "missed". Intensivists at the Austin Hospital in Melbourne have developed and trialed a "death audit tool", which effectively is an administrative procedure whereby the circumstances of every single death occurring in a hospital are subjected to a questionnaire, which identifies whether the patient involved may have been a donor, and identifying the reasons why they were not (where in fact they did not become donors).

We understand that this "death audit tool" has been considered by the Australia & New Zealand Intensive Care Society (ANZICS) for national application. The results of a study of the use of the "death audit tool" in the first 8 months of its operation in Victoria have been remarkably instructive. They indicate that, through tracking each hospital death, donating hospitals may have missed 20 donors. In a full year, using 1998 figures, such an increase would lift the total numbers of donors for Vic/Tas from 40 to 66, and the donation rate would lift from 8 donors pmp to 14.3 dpmp.

Use of a "death audit tool" is a significant part of the international "Donor Action" scheme, whose creation was funded by multinational pharmaceutical company Novartis Pharmaceuticals, and which is offered at no charge to donor agencies around the world as a tried and proven method of integrating donor identification and management services within donating hospitals. Since "Donor Action" is capable of being adjusted to suit local or regional conditions, it may be useful in the case of Queensland as your State moves to a centralised agency.

A copy of the outline of the "Donor Action" system is appended at Attachment 7 for the Committee's information.

WE RECOMMEND THAT

(i) The Committee endorse the use of the "death audit tool" for the identification and management of potential organ/tissue donors in Queensland donating hospitals;

(ii) The Committee recommend the investigation of the possible application of "Donor Action" as an integrated scheme of donor management in Queensland donating hospitals.

E. PUBLIC EDUCATION PROGRAMMES - THE NEED FOR PUBLICATION OF COMMON MESSAGES NATIONWIDE

We presume that part of the work programme of Queenslanders Donate will be to publicly promote the community value of organ/tissue donation.

We wish the Committee to know that, since Australians are mobile with respect to their domicile, and since a national allocation protocol means that organs are shipped interstate according to need, it is important that a common message with regard to the mechanics of donation are published.

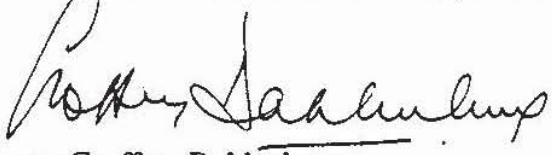
Australians Donate's predecessor organisation, ACCORD, did much work toward bringing together the format and text of items such as brochures and donor cards, and Australians Donate is continuing that work with the hope and expectation to shortly have one of each covering all of Australia.

Australians Donate maintains a national freecall 1800 telephone information service, and disseminates widely the information on public sentiment gleaned by this medium. Australians Donate is also working toward the establishment of a national donor database, which would be accessible nationwide regardless of the potential donor's domicile, and which would contribute toward relieving the stress of anxiety and uncertainty with respect to donor status which is abovementioned.

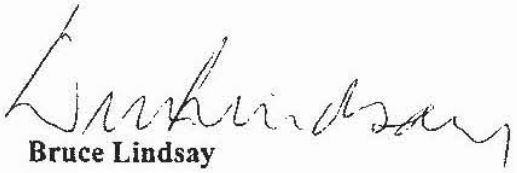
WE RECOMMEND THAT

The Committee support the involvement of Queenslanders Donate within efforts by Australians Donate to standardise public education programmes regardless of jurisdiction.

Submitted on behalf of Australians Donate, and the South Australian Organ Donation Agency, by



Professor Geoffrey Dahlenburg
Member, National Council, Australians Donate
Director, South Australian Organ Donation Agency



Bruce Lindsay
National Director
Australians Donate

INQUIRY INTO THE TRANSPLANTATION AND ANATOMY AMENDMENT BILL 1998

SUBMISSION FROM AUSTRALIANS DONATE and the SOUTH AUSTRALIAN ORGAN DONATION AGENCY

LIST OF ATTACHMENTS

1 List of Members and the agencies which they represent on the National Council of Australians Donate

2 1998 Annual Report of the South Australian Organ Donation Agency

3 Copy of letter to Queensland Minister for health re the Bill

4 Extract showing donation rates by State from 1986 to 1998

5 Paper "Listing of Organ/Tissue Donors on Drivers' Licences - The Next Step"

6 Summary Findings of "Organ Donor Status on Driver's Licences" Survey, Australians Donate, August 1998

7 "Donor Action Working"

COUNCIL MEMBERS - AUSTRALIANS DONATE

Salutation	Name	Position	Organisation	Address1	Address2	Address3	Phone
His Excellency Sir Eric Neal	Sir Eric Neal AC CVO	Chairman Australians Donate National Council, Governor of South Australia		Government House GPO Box 2373	ADELAIDE SA 5001		ph 08 8223 6166 fx 08 8359 2690
Mr Prime	Mr Warwick Prime	Chief Executive Officer	Australian Kidney Foundation	GPO Box 9993	ADELAIDE SA 5001		ph 08 8267 4555 fx 08 8267 4450
Mr Stone	Mr Ross Stone	President	Silent Hearts	PO Box 839	BOWRAL NSW 2576		ph 02 4861 6400 mobile 0412 147 317 fx 02 9913 7213
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Mr Hyde	Mr Graham Hyde	Chairman	Queensland Transplant Services Specialist Advisory Panel	Bayside District Health Service, PO Box 9312	WYNNUM PLAZA QLD 4178		ph 07 3893 8406 fx 07 3893 0169
Professor House	Professor Anthony House	Professor of Surgery	Department of Surgery	Queen Elizabeth II Medical Centre	NEDLANDS WA 6009		ph 08 9346 2148 fx 08 9346 2416
Mr Robertson	Mr Paul Robertson	President ATCA	Transplant Coordinator, Pancreas Unit	Westmead Hospital, Hawkesbury Rd	WESTMEAD NSW 2145		ph 02 9845 7891 fx 02 9633 9351
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Professor Dahlenburg	Professor Geoffrey Dahlenburg	Director	SA Organ Donation Agency	10 Pulteney St	ADELAIDE SA 5000		ph 08 820 fx 08 820
Professor Scott	Professor David Scott		Royal College of Surgeons	Suite 10, 212 Clayton Rd	CLAYTON VIC 3168		ph 03 954 fx 03 954
Dr Tobin	Dr Bernadette Tobin	Director	John Plunkett Centre for Ethics	St Vincent's Hospital	Victoria St	DARLINGHURST NSW 2010	ph 02 936 fx 02 936
Dr Duncan	Dr Alan Duncan	Dean, Faculty of Intensive Care	Australian and New Zealand College of Anaesthetists	C/- Paediatric Intensive Care Unit	Princess Margaret Hospital for Children	GPO Box D 184 PERTH WA 6001	ph 08 934 fx & ph 08 938
Dr Feek	Dr Colin Feek	Chief Medical Advisor	Ministry of Health	PO Box 5013	Wellington NEW ZEALAND		ph 0011 6 fx 0015 64
Mr Abbenbrock	Mr Brett Abbenbrock	Clinical Nurse Consultant, Emergency Services	Prince of Wales Hospital	High Street	RANDWICK NSW 2031		ph 02 938 fx 02 938
Ms Ireland	Ms Lyn Ireland	Head of Donor Tissue Bank	Victorian Institute of Forensic Medicine	57-83 Kavanagh St	STH. BANK VIC 3006		ph 03 968 fx 03 9686
Mr Broadhead	Mr Peter Broadhead	Assistant Secretary, Rural Coordination & Special Access Program Branch	Dept of Health & Family Services	GPO Box 9848 MDP2	CANBERRA ACT 2601		ph 02 628 fx 02 6289
ANZICS REPRESENTATIVE	TO BE ANNOUNCED						
AUSTRALIAN RED CROSS BLOOD SERVICE	TISSUE TYPING LABORATORY REPRESENTATIVE	TO BE ANNOUNCED					
Mrs Thorn	Mrs Jan Thorn			17 Murray Street	ANGASTON SA 5353		ph & fax 0 mobile 04
Mr Wright	Mr Garry Wright			U1/303 Montacute Rd	ATHELSTONE SA 5076		mob 0418 1 home ph 0

Attachment 1.

Attachment 2.

Annual Report of the Activities of the South Australian Organ Donation Agency

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1998

Professor Geoffrey Dahlenburg

Karen Herbertt PSM

CONTENTS

The South Australian Organ Donation Agency

Congratulates

Karen Herbertt

on the Award of the

Public Service Medal

For Services to the Community in the Area of Organ Donation and its Organisation

South Australian Organ Donation Agency

1. Vision and Mission Statement and Organisational Structure

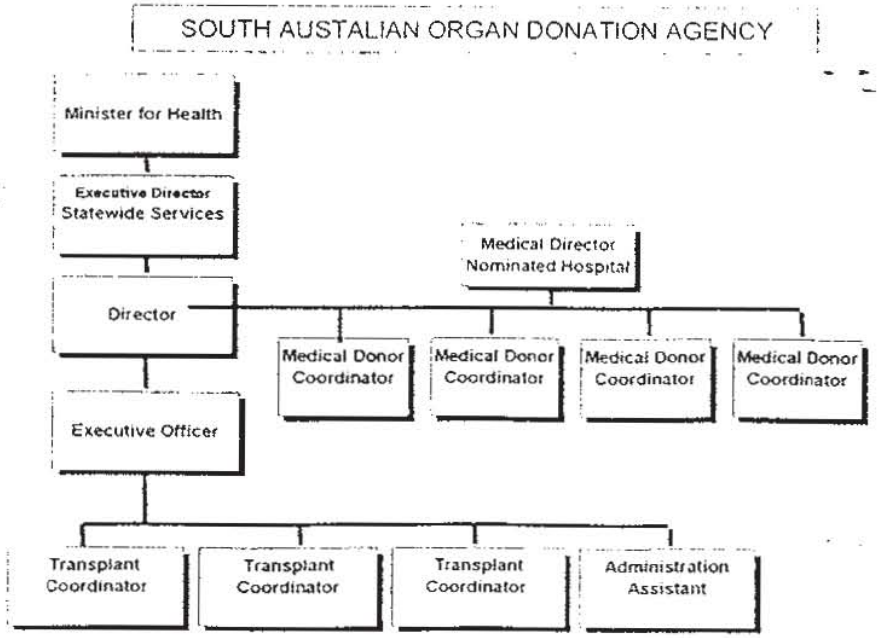
The South Australian Organ Donation Agency was formed in June 1996, with the Vision Statement "To ensure best practice in organ donation" and the Mission Statement:

- To promote awareness of organ donation within the community
- To recognise and meet the needs of recipients
- To preserve fully the dignity due to donors and;
- To recognise and meet the needs of donor families

SAODA is funded by the Department of Human Services and is managed by a Director, a Manager and an Administrative Assistant. Administrative Support is provided centrally to three Donor Coordinators (non medical) who work with Medical Donor Coordinators within the major hospitals (Table 1).

The Management Committee meets regularly to discuss potential and actual donors in all hospitals, death audits and the future development of the Agency.

Table I



2. Medical Donor Coordinators and Donor Coordinators

Medical Donor Coordinators

Medical Donor Coordinators are all senior Intensive Care Consultants who have extra duties including:

- To identify within the Intensive Care Unit and other areas of the hospital any potential organ donors.
- To discuss with relatives, in conjunction with the Donor Coordinators, the option of organ donation.
- To provide medical assistance to the Donor Coordinator in the initial stage of the donation process.
- Responsibility for the clinical management of the donor.
- To identify issues that influence (that is assist or limit) donor procurement in general or within the specific hospital.
- The provision of education within the hospital and;
- Providing the Intensive Care perspective of organ donation in policy making committees.

The Agency reimburses the Intensive Care Unit for these services

Donor Coordinators

The role of the Donor Coordinator (previously called Transplant Coordinator) has effectively been unchanged regarding donor related activities. The Medical Donor Coordinator would generally refer the potential donor to the Donor Coordinator. The Team would then approach the family to discuss organ donation. This Team approach has proven to be very successful. The Donor Coordinator makes all of the donor arrangements including tissue typing, virology testing, liaising with transplant units, operating theatres and ICU.

Education is provided to hospital staff and the community. They also provide the essential immediate support and follow up care for the relatives of the donor. It is the latter task which is so important to a successful organ donation programme.

The Donor Coordinator thus has support within the Intensive Care Unit and any issues and problems can be addressed via the Medical Donor Coordinator.

3. Activities Relating to Organ Donation

3.1 Summary

In the year 1998 the organ donation rate rose to 23 donors per million population (dpmp) compared to 18 dpmp in the previous year.

This compares very favorably with the national donation rate for 1998 of 10.5 dpmp.

The very positive result reflects our belief that the most important factor in increasing the organ donation rate is the assiduity with which hospital intensive care staff identify potential donors and, with a coordinated and sensitive approach to the relatives of the potential donor, obtain permission for organ donation.

The application in South Australia of the slightly modified Spanish model of organ donor procurement can thus be deemed successful. This approach to organ donation was established as a trial by the Australian Health Ministers Advisory Council (AHMAC).

3.2 Details of Activities

a) Solid Organ Donor Referrals in South Australia

	1998	1997	1996	1995	1994	1993	1992	1991	1990	1989
REFERRALS	62	58	57	52	53	53	52	37	36	33
ACTUAL DONORS	38	29	28	24	23	26	20	17	28	21

There were 25 referrals in which organ donation did not eventuate. The reasons being:

Medical Contraindications	10
Family Refusals	11
Patient's Wish not to Donate	1
Other	2
TOTAL	24

Tissue Only Referrals (Eyes/Bone)

	1998	1997	1996	1995
Tissue Donors	9	5	5	10
Eyes*	16	10	10	20
Bones	4	2	4	

* The 'eye donors' are those referred through SAODA, and are separate from those eye donors obtained by the Eye Bank.

b) *Organ Donor Referrals by Hospital in 1998*

The following table shows the referrals and actual organ donors by hospitals. It also indicates by hospital, the reason why the referral did not eventuate into a donation.

HOSPITALS	REFERRALS	ACTUAL DONOR	FAMILY REFUSAL	DONOR WISHES	MEDICALLY UNSUITABLE	OTHER
RAH	24	13	5	1	5	
QEH	7	5*	-	-	2	
FMC	17	12	4	-	1	-
WCH	4	3	1	-	-	-
DARWIN	3	2	-	-	-	1
ALICE SPRINGS	3	1	-	-	2	
MEMORIAL	1	1	-	-	-	-
ASHFORD	2	1*	1	-	-	
MODBURY	1	-	-	-	-	1
TOTAL	62	38	11	1	10	2

* 2 non heart beating donors

c) *Family Refusal by Hospital*

Refusal rate based on only those who were asked, not the total number of referrals

	RAH	FMC	WCH	QEH	DAR	A/SP	ASHF	MEM	TOTAL
REQUESTS	19	16	4	5	3	1	2	1	51
FAMILY REFUSAL	5	4	1	0	0	0	1	0	11
REFUSAL %	26%	25%	25%	0%	0%	0%	50%	0%	22%

The overall family refusal rate of 22% is very low compared with other countries – The rate in Spain in 1995 being 25% and in an Australian Survey[1] the refusal rate was 56%.

1. Obtaining Consent for Organ Donation in Nine NSW metropolitan Hospital Chapman JR, Hibberd AD, McCosker C et al ANAESTH INTENS CARE 1995.23.81-87

d) *The Causes of Death of Donors (1998)*

CAUSE	NO. OF DONORS	%
Cerebral Hemorrhage	18	49%
Road Trauma	6	16%
Non Road Trauma	2	5%
Other	2	5%
Hypoxia	7	16%
Brain Tumour	2	5%
Gun Shot	1	3%
TOTAL	38	100%

The number of donors from road trauma has fallen from 28% in the years 1990-96 to 12% in 1997. The slight increase in 1998 reflects the increase in that year in fatal road accidents.

e) *Range of Organs Donated from Solid Organ Donors*

HOSPITALS	KIDNEY	LIVER	HEART	LUNG	EYES	BONES	HEART VALVE	PANCREAS
RAH	24	8	6	10	8	2	2	1
QEH	8	2	2	4	-	-	-	-
FMC	17	6	1	4	16	-	2	-
WCH	4	3	1	-	-	-	-	1
DARWIN	4	2	1	4	-	-	-	-
AL/SPRINGS	2	1	1	2	-	-	-	-
MEMORIAL	2	1	-	-	-	-	-	-
ASHFORD	2	-	-	-	-	-	-	-
TOTAL	63	23	12	24	24	2	4	2

f) *Donor Profile in 1998*

There were 19 females and 19 males who were donors. The age of donors was 1-73 years. The mean age was 40.9 years and the median age was 47 years. There were 6 donors over 60 years.

g) *Recipient Units*

SA provided organs to the following Transplant Units.

i. Heart Units

HOSPITAL	HEARTS	HEART VALVE	HEART/LUNG BLOC	LUNG	
				SINGLE	DOUBLE
Alfred (VIC)	5	-		4	4
Royal Children's (Victoria)	1	-		-	3
St Vincents (NSW)	1	4	1		2
Prince Charles (QLD)	2	-			0
Royal Perth (WA)	2	-			0
TOTAL	11	4	1	4	9

ii) Liver Units

HOSPITAL	LIVERS
FMC	6
Princess Alexandra (QLD)	7
Royal Prince Alfred (NSW)	5
Austin (VIC)	3
Sir Charles Gardiner (WA)	2
TOTAL	23

There were 8 liver transplants performed at the FMC

iii Pancreas Units

HOSPITAL	COMBINED KIDNEY/PANCREAS
Monash Medical Centre (VIC)	1
Westmead (NSW)	1
TOTAL	2

iv) Kidney Units

There were 63 kidneys transplanted from 34 donors, of these 54 kidneys were transplanted in SA. There were 3 donors not medically suitable for kidney donation however were able to donate other organs. There were 2 dual transplants (1 horseshoe and 2 kidneys transplanted into 1 recipient). 1 kidney was congenitally absent, 4 kidneys were unsuitable based on biopsy results.

STATE	KIDNEYS SENT	KIDNEYS RECEIVED
Victoria	3	4
New South Wales	3	4
Queensland	1	1
Western Australia	2	1
TOTAL	9	10

SA received 12 interstate kidney offers and accepted 10 kidneys.

Kidney Transplants in South Australia

STATE	QEH	WCH
Cadaveric Donor	62	2
Live Donor	20	0
TOTAL	82	2

The following tables reflect the changing pattern of the process of organ donation in this state nationally over the last 10 or so years.

h) Comparison of Donor Numbers by State - expressed as donors per million of population

	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998
SOUTH AUST/NORTH TER	21	9	14	14	16	11	12	16	14	15	17	17	23
QUEENSLAND	17	14	19	13	13	15	22	14	12	11	11	11	12
NEW SOUTH WALES/ACT	10	10	12	15	13	12	11	12	11	11	11	10	10
VICTORIA/TASMANIA	11	13	13	14	10	10	9	12	7	8	10	9	8
WESTERN AUSTRALIA	13	11	9	11	7	14	8	11	9	10	7	4	7
TOTAL	**13**	**11**	**13**	**14**	**12**	**12**	**12**	**13**	**11**	**11**	**11**	**10**	**10.5**

i) Donors by Hospital in South Australia 1982- 1998

	1982	1983	1984	1985	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998
RAH	12	6	7	10	14	8	12	9	14	10	9	9	10	10	14	9	13
FMC	8	8	4	5	7	1	2	5	6	3	6	6	7	9	6	10	12
QEH	1	2	14	1	7	3	4	2	3	0	4	3	4	2	2	3	5
WCH	1	1	1	0	3	0	1	3	2	2	1	0	2	1	3	1	3
DARWIN					4	2	3	2	1	2	0	3	0	0	2	4	2
MODBURY								0	2	0	0	1	0	0	0	0	0
ASHFORD												1	0	0	0	2	1
LYELL McE											0	3	0	1	0	0	0
A/SPRINGS													1	1	1	0	1
MEMORIAL																	1

j) Cadaveric Organ Donors in South Australia 1982- 1998

	1982	1983	1984	1985	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998
MALE				9	27	11	16	13	17	11	8	20	12	7	21	20	19
FEMALE				7	8	3	6	8	11	6	12	7	12	17	7	9	19
TOTAL NO.	22	17	26	16	35	14	22	21	28	17	20	26	23	24	28	29	38
AGE RANGE (yrs)				11-51	2-67	12-51	6-52	1-65	4-62	7-61	11-69	13-70	15mth -69	10-71	6-69	15-72	1-73
MEAN				32	28	23	30	29	32	32	43	38	29	40	36.5	43.5	40.9
MEDIAN				35	22	19	28	25	34	29	46	38	38	44	36	46	47

k) Donor Cause of Death in South Australia 1985- 1998

	1985	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998
ROAD TRAUMA	8	19	6	7	8	12	6	4	8	4	3	11	4	6
OTHER TRAUMA	1	5	4	4	1	3	3	1	2	3	2	4	2	2
CEREBRAL HAEM.	7	7	2	7	8	7	4	13	12	12	14	10	14	18
GUNSHOT	0	2	1	4	4	3	0	3	0	1	1	1	2	1
BRAIN TUMOUR	0	1	0	0	0	1	3	0	0	0	2	1	4	2
HYPOXIA	0	0	1	0	0	1	2	1	3	3	0	1	3	6
ASTHMA	0	1	0	0	2	1	1	0	2	0	1	0	0	1
CEREBRAL INFECTION	0	0	0	0	0	0	0	0	0	0	3	0	0	1
POISON	0	0	0	0	0	0	0	1	0	0	1	0	0	1
TOTAL	16	35	14	22	23	28	19	23	27	24	24	28	29	38

I) Organs Retrieved in South Australia 1986- 1998

	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998
KIDNEYS	70	28	44	42	32	34	35	48	42	47	54	50	63
LIVERS	1	1	1	6	6	6	9	13	12	19	17	19	23
HEARTS	0	0	1	7	12	8	9	13	10	11	15	12	11
HEART/LUNG BLOC	0	0	0	0	0	2	2	0	2	1	1	0	1
LUNGS	0	0	0	0	2	0	2	17	14	18	24	18	22
PANCREAS	0	0	0	4	1	0	2	1	0	0	0	0	2
EYES	0	0	12	24	28	10	12	20	20	21	18	13	24
BONE	0	1	3	5	3	5	5	4	6	2	6	2	2
TENDON	0	0	0	6	0	0	0	0	0	0	0	0	-
SKIN	0	0	0	0	0	0	0	0	1	1	0	0	-
HEART VALVE	0	0	0	1	6	2	1	4	6	2	2	1	4
TOTAL	71	30	61	95	90	67	77	120	113	113	137	115	152

4. Auditing Deaths in Donor Hospitals

Initially a pilot study was performed at Flinders Medical Centre. The universal hospital in-patient separation system which codes each in-patient episode using the international classification of diseases, 9th revision, clinical modification (ICD-9-CM) was used to generate organ donor indices, The quality and consistency of this data is high because of the central role it plays in hospital funding[2].

All ICD-9-CM codes were reviewed looking for diseases or pathological processes that may potentially result in brain death. In this pilot study the separation codes of all adult organ donors in South Australia for the period 1988 to 1995 inclusive were examined. All donor patients came from three tertiary hospitals and their codes fell into three groups; head injury, cerebrovascular accidents (CVA) and other. The results of the pilot study are shown in the following table.

Group	Codes	Number	(%)
Head Injury	800-801 803-804 850-854	68	(44.2)
CVA	430-434 436	65	(42.2)
Others		21	(13.6)
CNS tumours	191-192	4	
Anoxia	348.1	5	
Asthma	493	5	
Cardiac arrest	427.5	3	
Cerebral oedema	348.5	1	
Ventricular tachycardia	427.1	1	
Asphyxia/Respiratory arrest	799.0-799.1	1	
Strangulation	994.7		

Following this pilot study the South Australian Organ Donation Agency reviewed deaths in the five public hospitals, to ascertain whether donors were "missed" and to estimate the realistic donor potential. The Ethics Committee at each of these hospitals gave permission for the study. A full print out of all deaths with separation codes was obtained each month from the records section of each hospital. This complete list was perused and the information regarding potential donors obtained.

At each Management Meeting the details of each potential donor is reviewed and in other cases the reasons for family refusal discussed.

2. Hogeman GK, Holt A, Vedig AE et al. Transplant Proc. 1997 8 3305 - 3306

5. Care of Donor Families

The SA Organ Donation has a "shop front" office in the Central Business District of Adelaide. Our office is very deliberately not in a hospital. Families are often reluctant to return to the hospital in which their relative has died. To maximise support for donor families, an independent office is essential.

Donor families are encouraged to call into our office at any time and the community can easily access information on organ donation. The Agency contracts the services of independent counsellors for donor families. This service provides multi- lingual counsellors who can be utilised in any Australian state. There is no charge for donor families for this service.

The Agency has been supportive of the establishment of a Donor Family Support Group named G.I.F.T. (Given in faith and trust)
The overall aims of the group are:

- Moving On: to develop necessary skills and strategies to move on with life following the loss of a relative.

- Support: to develop a support network within the group. We believe that people with similar experiences can offer much to others.

- Education and awareness: many donor families have expressed a desire to develop an outward focus in regard to community education / awareness. This ensures donor family representation to relevant groups.

The group is supported by an independent bereavement counselor. They meet once a month and produce a quarterly newsletter. A bereavement workshop for donor families was held in November 1998.

The full area of support given to donor families is listed below.

a) Support in ICU from the Donor Coordinator, who cares for them during the "requesting permission for donation time", and is the "relatives advocate" in theatre during the donation process.

b) All the Donor Coordinators (previously called Transplant Coordinators) have university qualifications in bereavement counselling.

c) The Donor Coordinators arrange for a viewing of the donor after theatre (if desired).

d) Follow up phone calls

   i. the day after donation

   ii. 1-2 weeks later

iii. 2-3 days after sending out the Bereavement Package (see below)

e) Bereavement Package – This package has been produced by SAODA with contribution from donor families.

f) GIFT – The Donor Family Support Group. Established and supported by SAODA. Information about this is sent with the Bereavement Package.

g) GIFT Newsletter – This letter goes to all those donor families who remain on the "ongoing mailing list".

h) Loss & Grief Workshop for Donor Families – These are attended by a University Lecturer in Counselling.

i) Linkage of Donor Families – In support to donor families, if Support Groups are needed, matching of similar support group to the requesting donor family is made, ie if a child becomes a donor, support to that family is given by a donor family who had a similar loss.

j) Follow up support is given as much as needed.

k) Bereavement Counselling – When requested bereavement counselling is provided by OCAR or Quest.

l) The yearly Thanksgiving Service and the Dinner following is an opportunity for donor and recipient families to give thanks, and, with others, to remember those who became organ donors.

m) The Donor Coordinators teach hospital staff, particularly in ICU, about organ donation and the donor family's reactions.

However, given all of the above supports that are available, we acknowledge that every donor family is unique and will require different levels of support and involvement.

Plans for 1999

In addition to the above, SAODA is planning to provide the following services to donor families, commencing in 1999.

- A teleconferencing support service for families in country and interstate areas, as well as those who are unable to attend GIFT meetings. This service is presently offered in NSW with successful outcomes.
- Workshop to provide donor families with some very basic skills to assist them when networking with other donor families.
- Organ donation will be included on the grief and loss website called Grieflink. This project is in conjunction with the Department of General Practice, University of Adelaide.

6. Organ Donor Awareness and Education Committee

The 1997 Annual Report outlined the aims and rationale for this Committee.

The Committee met 3 times during the year and one of its major functions was to establish a booth at the Royal Agricultural Show in September. This booth was staffed day and night from volunteers from all groups with representatives on the committee – it was a great success and helped raise community awareness.

7. Presentations by Members of SAODA in 1998

The following presentations, articles and activities have been made by members of SAODA during 1998.

GW DAHLENBURG

- The South Australian Model of Organ Donation February 24th – Invited Presentation to the Minister for Health and Department of Health, Western Australia.

- Organ Donation in South Australia – Guest Speaker, AGM Australia Institute of Medical Scientists, 24 July 1998.

- Organ Donation ~The Procurist View – Invited Presentation. Aust NZ Intensive Care Society. Annual Scientific Meeting, 9 October 1998.

- Contribution of the Spanish System of Organ Donation to the South Australian Model – Invited Address: The Spanish Model for Transplants and its International Impact, 20 October 1998. Foundation for Health Services, Madrid Spain.

National Committees

Chairman - Donor Action National Steering Committee

Member - ADAPT Steering Group

Member - National Council – Australians Donate

KAREN HERBERTT

Major Presentations

- Two year Experience in Auditing Deaths in 5 Public Hospitals in South Australia , ATCA Conference April 1998
- Taking the Next Step – A Donor Family/Transplant Recipient Contact Register, ATCA Conference April 98
- The Intrinsic Component of Organ Donation: Care and Support – Silent Hearts Australia Donor Family Conference
- Transplant Nurses National Conference Invited Speaker – Increasing Organ Donation ~ SA Model in Action.

Publications

- Australian and New Zealand Organ Donation Registry with Russ GR 1998
- How Can Organ Donation Rates be Improved Young RJ, Herbertt KL, Australian Anesthesia 1998.

Presentations to the Following Groups

Community Groups	4
University Groups	2
School Groups	1
Hospital Groups	6 (including Alice Springs)
Professional Groups	7
Other	6

KATHY HEE

Master Thesis

A Pilot Study on the planning, implementation and evaluation of an Organ Donor Family Support Group in South Australia (Thesis approved 1998)

Presentation on Organ Donation to the Following Groups

Community Service Groups (Lions, Rotary, Probus etc)	9
University Groups	3
School Groups	1
Hospitals Groups (Nurses, ICU staff, theatre staff, etc)	11
Professional Organisations (Transplant Nurses, ADAPT, ABC etc)	3

Ms Hee was awarded the degree of Masters in Health Counselling from the University of South Australia.

GLENYS HODGEMAN

- Donor/Recipient Communication – ATCA Meeting 1998

Presentations in Organ Donation to the Following Groups

• Community Service Groups	3
• University Groups	3
• School Groups	1
• Hospital Groups	4
• Professional Organisations	1
• Other Groups	1

MARY KELLY

- Coordinator – Thanksgiving Service May 1998

Master Thesis

A Pilot Study on the planning, implementation and evaluation of an Organ Donor Family Support Group in South Australia (Thesis approved 1998)

Presentation on Organ Donation to the Following Groups

Community Service Groups	1
University Groups	1
School Groups	3
Hospital Groups	8
Other Groups	1

Ms Kelly was awarded the Degree of Masters in Health Counselling from the University of South Australia.

AUSTR
DON

Australia's National Organ and Tissue I

Chairman: His Excellency Sir Eric Neal AC CVO, Governor of South Australia

Office: 677 South Road, Black Forest, South Australia 5035. Phone: (08) 8351 5222 Fax: (08) 8351 5522
Email ozdonate@camtech. net. au

Attachment 3.

25th February 1999

Hon Wendy Edmond MLA
Minister for Health
Queensland Government
GPO Box 48
BRISBANE QLD 4001

Dear Minister

RE: LEGISLATIVE MEANS OF INCREASING ORGAN/TISSUE DONATION

While Australians Donate has been for some time aware of the Private Member's "Transplantation and Anatomy Amendment" Bill 1998, we note with interest a brief report in today's "Courier Mail' that the Government is itself "working on its own proposal to address problems associated with organ and tissue donation".

Without commenting on the Private Member's Bill, may I bring to your attention one of the most concerning blockages in Queensland's use of donor status data as indicated on drivers' licences. We regard the aggregate of such donor status data as easily the most valuable resource on potential donors in Australia. Yet in at least two States - one of them being Queensland - Crown Law opinion has for some reason(s) declared that release of such data to donor coordinators is a breach of confidentiality provisions, and thus this information cannot be readily consulted.

May I stress to you the enormous value of enabling donor coordinators and ICU staff to have foreknowledge of the donor status of potential donors? There is no doubt that hospital staff suffer considerable stress from the uncertainty of not knowing whether or not a possible donor has indicated a wish to donate, as do the donor's family, at a time already charged with emotion, stress and grief. To know that person's donor status before requesting donation relieves such stresses as may be expected to increase the probability of donation proceeding.

We operate national freecall 1800 information lines on organ and tissue information, and one of the most frequent requests is for assurance that intending donors' wishes will be carried out after their death. Although we would like to reassure such callers that information which they have placed on their licences will be made available to donor coodinators, at present we cannot do so.

Generously supported by Australian Commonwealth, State and Territory Governments, and

JANSSEN-CILAG IMMUNOLOGY AND TRANSPLANTATION NOVARTIS

Roche Transplantation

Evidence, including a survey undertaken in Victorian hospitals, indicates that, where a potential donor's positive donor status is known at the time of making the request to the donor's family, consent will always be given to donate; but where such intent is not known, refusal rates run as high as 39% (at least in the Victorian survey).

In other words, we believe that the measures proposed in the Private Member's Bill (which we fear would be found unpalatable by many within the community) may not be necessary in order to lift donation rates. Rather, a move as simple as legislating for the release of donor status from licences to donor coordinators may have the same effect, but without the political risk.

If you choose to move in this direction, please may we suggest that at the same time you might address the question of the means of access to the data, since in this way Queensland has the opportunity to lead the rest of Australia. Australians Donate is currently negotiating with the Transplant Promotion Council (TPC) in Victoria, for the establishment of a single national donor database. It is planned that this database will be accessible 24-hours daily by donor coordinators around Australia, by encoded electronic access. We currently have a proposal before a major computer hardware supplier, for the furnishing of all donor coordinators with modem-equipped laptop computers, to facilitate such access.

We would therefore ask you, please, to consider building into whatever measures you might be considering, the following elements:

(a) legislating in favour of deeming a driver's licence holder's signed annotation of donor status to be exempt from confidentiality requirements which would otherwise disallow the provision of such data to legitimate enquirers such as donor coordinators and ICU staff;
(b) legislating to permit the provision of such data (masked from other licence and personal data, other than to positively identify drivers who have "ticked the box") to appropriate persons;
(c) legislating (if necessary - this provision may be able to be accomplished by Regulation or by administrative means) to permit the periodic downloading of updated masked data on positive donor status, and its provision to a single national database, so that it may be accessed by donor coordinators by a single call nationally.

Minister we would be eager to supply you with any information/evidence/data to support any such legislative revisions in Queensland, and we would be very happy to support in any way your Government's efforts to lift organ and tissue donation. For your information I am including data on organ donation by State for the calendar year 1998.

Yours sincerely

BRUCE LINDSAY
National Director

Attachment 4.

The following tables reflect the changing pattern of the process of organ donation in this state nationally over the last 10 or so years.

h) Comparison of Donor Numbers by State - expressed as donors per million of population

	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998
SOUTH AUST/NORTH TER	21	9	14	14	16	11	12	16	14	15	17	17	23
QUEENSLAND	17	14	19	13	13	15	22	14	12	11	11	11	12
NEW SOUTH WALES/ACT	10	10	12	15	13	12	11	12	11	11	11	10	10
VICTORIA/TASMANIA	11	13	13	14	10	10	9	12	7	8	10	9	8
WESTERN AUSTRALIA	13	11	9	11	7	14	8	11	9	10	7	4	7
TOTAL	**13**	**11**	**13**	**14**	**12**	**12**	**12**	**13**	**11**	**11**	**11**	**10**	**10.5**

i) Donors by Hospital in South Australia 1982- 1998

	1982	1983	1984	1985	1986	1987	1988	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998
RAH	12	6	7	10	14	8	12	9	14	10	9	9	10	10	14	9	13
FMC	8	8	4	5	7	1	2	5	6	3	6	6	7	9	6	10	12
QEH	1	2	14	1	7	3	4	2	3	0	4	3	4	2	2	3	5
WCH	1	1	1	0	3	0	1	3	2	2	1	0	2	1	3	1	3
DARWIN					4	2	3	2	1	2	0	3	0	0	2	4	2
MODBURY								0	2	0	0	1	0	0	0	0	0
ASHFORD												1	0	0	0	2	1
LYELL McE											0	3	0	1	0	0	0
A/SPRINGS													1	1	1	0	1
MEMORIAL																	1

Attachment 5.

LISTING OF ORGAN/TISSU
LICEI

DISCUSSION PAPER ON "THE NEXT STEP"

BACKGROUND

Most States and Territories in Australia currently offer the holders of drivers' licences the option of listing their willingness to become organ/tissue donors in the event of their death. (The most notable departure from these arrangements is in the State of Victoria, where the State Government and pharmaceutical company Glaxo Wellcome share equally the costs of establishing and administering the Victorian Organ Donor Registry. At time of writing, that Registry listed fewer than 3% of that State's licence holders as being willing to be considered donors in the event of their death. It is also significant that tissue is not mentioned in that Registry's title).

While such a move is well-intentioned, it cannot achieve its potential value as far as confirming the potential donors' intentions since

a. the circumstances of accidental death seldom mean that intensive care staff are aware of the contents of potential donors' wallets/personal effects;
b. since presently there is no central register of such intentions which is nationally accessible, there is considerable risk that potential donors' intentions with respect to organ/tissue donation may either be overlooked or not discovered in time to permit donation of solid organs to occur, especially when they die interstate;
c. there is the danger that the method by which licence-holders indicate their intentions cannot be said to be truly "informed consent";
d. there is no mechanism whereby holders are encouraged to discuss their intentions with their next-of-kin, or preferably add their co-signature to their intention as indicated by their licence application, and
e. in some jurisdictions, the value of licence indications is negated because the information is not released to donor co-ordinators in such fashion as will assist in the speedy identification of potential donors.

This paper therefore examines ways in which the system for listing and then releasing information on licence records about potential donors might be modified, with the view of rendering this system truly national and immediate in its value.

2.

CONSIDERATION OF THE ISSUES

a. **Relieving the pressure of uncertainty about a potential donor's wishes with respect to organ/tissue donation, when an approach is made to the donor's family.**

Experience shows that, at a time of enormous emotional stress both for ICU staff and for the potential donor's family, the decision on whether to allow donation to proceed is rendered considerably easier for all concerned when the potential donor's wishes are known.

In other words, the "conversion rate" from potential to actual donor improves where there is some certainty about the potential donor's wishes.

Further, empirical evidence shows that approaches by ICU staff to traumatised relatives of the potential donor are far more likely to succeed in securing donation where the family has already been engaged in discussion about their family member's wish to donate upon death, the concept of "brain death", and the processes involved.

Presently the means by which licence-holders indicate willingness to become organ/tissue donors vary according to their State or Territory of origin. It is however fair to generalise that in no jurisdiction are licence applicants supplied with such information about the process and end-value of organ/tissue donation as could be construed to be "informed consent" in marking their licences to indicate their willingness to become donors, nor is there presently any mechanism whereby applicants may be encouraged or required to seek endorsement by their next-of-kin about their intention to become donors.

Perhaps the most positive means of identifying potential donors is practised in Western Australia, where persons admitted to any hospital in that State, and where they have indicated on their drivers' licences their intention to become donors in the event of their death, have their status as far as their licences are concerned marked on the "Patient Master Index" (PMI) which accompanies them throughout their hospital stay. While this system is optimal in terms of recognition of intending donors, practices in other States and Territories mean that nationalisation of the PMI scheme may not be possible in the short- to medium-term.

RECOMMENDATION 1:

That State and Territory motor registration authorities be approached with a view to making available, at time of offering new or renewed driving licences, such information as would render applicants' consent to donate truly informed;

3.

RECOMMENDATION 2:

That State and Territory motor registration authorities be offered such packaged information kits as would encourage them to ensure that counter staff are either sufficiently well informed about the process and end-value of organ/tissue donation as to respond to enquirers' questions, or that they are in a position to refer them to sources of information to respond to such queries; and

RECOMMENDATION 3:

That State and Territory motor registration authorities be requested to include on driving licence application material an encouragement to licence holders to discuss and seek endorsement from their families with respect to their wish to become organ/tissue donors in the event of their death.

b. **Development of a national register of donors via the licence application system.**

There is now in place, or in process of being rapidly developed, a scheme of donor co-ordinators working from centralised offices in each State in which facilities exist to undertake transplantation of organs/tissue.

While detail processes vary according to jurisdiction, it is generally the task of such co-ordinators to care for the interests of the families of potential donors, including in most cases the requirement that they (either themselves or in collaboration with ICU staff) approach the families of potential donors at the time of their diagnosis of brain death, with a view to securing permission to remove organs/tissue.

Such requests are made at times of extreme emotional stress on the families of potential donors, and not a little stress on the part of ICU staff. While the rights and needs of the donor families must always be paramount (since the act of donation is truly donation, not "procurement"), these requests are also made under the stress applied by time-limits, narrow or very narrow dependent on the organs which may be removed, which must be observed if the organs/tissue are to be removed in such a way as to maximise their chance of proving viable in recipients.

The value of a nationally-accessible donor data base would be to remove the uncertainty faced by donor co-ordinators and ICU staff at the time of requesting donation, and therefore by extension to reduce the stress on all concerned at that time. This certainty would also help to leaven the likelihood of converting intending donors to actual donors, through the removal of much of the "personal bias" factor from the request procedure. In other words, if the intending donor's wishes are not only known but are readily accessible to donor co-ordinators and ICU staff, the resistance encountered in some hospitals and units to loading already-pressing schedules with the requirements of securing donations may well be either mollified or removed.

It is also reported that the carriage by intending donors of donor cards is not sufficient to guarantee that the information on such intentions ever reaches the donor co-ordinators or ICU staff.

The mechanism by which a truly national database can be assembled from drivers' licence indications is open to debate, but it is evident that there are already
a. significant numbers of intending donors listed on licence information, and
b. access to such information varies from jurisdiction to jurisdiction.

It is **not** proposed that there be any attempt to establish a new database rather than an assemblage of existing information sources, although as the programme evolves it may be seen to be advantageous to download information from all sources onto a single and accessible listing.

RECOMMENDATION 4:

That State and Territory motor registration authorities agree in principle to making available, via access mechanisms to be developed with each jurisdiction, regularly updated data on those licence-holders who indicate a willingness to be noted as potential organ donors, so that a national database can be assembled and continually updated on the basis of licence data.

c. **Provision to licence-holders of such information on the practice, process and value of organ and tissue donation as would reasonably be construed to be "informed consent" in the event that they indicate their willingness to become donors upon their death.**

While Australians Donate and its predecessor, ACCORD, have developed information kits which are supplied to persons expressing interest in organ and tissue donation, there is currently no mechanism whereby applicants for drivers' licences can be adequately informed of the donation process at the time of making their application, and upon which they are then required to indicate their willingness or otherwise to become donors in the event of their death.

It is not reasonable to expect counter staff at motor registration authorities to be sufficiently informed about the donation issue as to respond to all enquirers' questions. It is however possible, with the agreement of the authorities, for Australians Donate to supply such quantities of information leaflets as may be inserted in licence renewal notices, or supplied with application material. It would be understood that such leaflets would need to be developed to physical specifications dictated by the format of mail-outs from each jurisdiction, and containing information which the authorities are comfortable to disseminate in this way.

RECOMMENDATION 5:

That motor registration authorities agree in principle to the inclusion, in printed material supplied to applicants for new or renewed drivers' licences, information relating to organ and tissue donation developed in association with Australians Donate.

d. <u>Inclusion in licence documentation of encouragement to intending donors to discuss their intentions with their next-of-kin.</u>

The experience of donor co-ordinators in all jurisdictions has been that, where intending donors have discussed their intentions with their families, the permission of the next-of-kin to proceed with organ and tissue donation in the event of the donor's death is almost guaranteed.

Similarly, there appears to be universal agreement that ICU staff and donor co-ordinators would welcome the relief from stress caused by uncertainty about the family's likely response to a request for donation. Comments made by donor families themselves indicate that they would welcome the opportunity to grasp the concept of "brain death" and to discuss the processes involved in organ and tissue donation away from the highly emotional and stressful environment in which they must come to terms with the imminent death of a family member.

It is however recognised that, while a model like the registration form used by the Victorian Organ Donor Registry - whereby next-of-kin are required to sign the form indicating that they have been consulted by the intending donor - is in this way ideal, the placement of steps and obstacles in the way of a licence applicant's completion of paperwork which is primarily routine and administrative may hinder rather than promote the value of donation.

RECOMMENDATION 6:

That such words be included on drivers' licence application material as will encourage applicants to discuss with their families their intention to register as donors.

e. <u>Removal of any potential legal impediment to the release of such information to outside agencies as will identify intending donors.</u>

Responses from motor registration and licensing authorities to requests for release of information varies across Australia.

Perhaps the most valuable is the approach of the Western Australian authority, which regularly downloads information on licence applicants who have listed themselves as intending donors, and supplies this data to that State's donor co-ordinators to allow updating of their State database.

In Queensland, however, the value of the licence system as an indicator of potential donors has been largely negated by a Crown Law opinion in that State, which concluded that release of such information as would identify intending donors (from drivers' licence applications) constitutes a breach of confidentiality provisions, and access to the database is denied to the donor co-ordinators.

RECOMMENDATION 7:

That such words be included on <u>any</u> expression of interest in becoming a donor, and specifically on drivers' licence application material, as will constitute authority by the intending donor to release such information as will identify them to donor co-ordinators or such other body as might become involved in assembling data for a national database.

BRUCE LINDSAY
National Director
Australians Donate

7th September, 1998

Summary findings of "Organ Donor Status on Driver's Licences" Survey, August 1998

SURVEY	*Queensland*	*New South Wales*	*Tasmania*	*South Australia*	*Western Australia*	*VIC*	*ACT*	*NT*
1. Organ Donor status on Driver's Licence	Yes	Yes	Yes, (Non-licence holders can also register)	Yes	Yes	No, VODR	Licence holders can attach a sticker	Licence holders can attach a sticker
2. Access to records	No, Restricted due to Privacy Act	Yes, Available to Donor/Tx Coordinators	Hospitals	No, Previously requested by AKF and refused	Yes, Download to coordinators via hospital mainframe		No record on database	Database is ready to accept info Awaiting changes to
3. # of Organ Donors recorded on database	1,142,760 (21 Nov 95)	1,465,510 (June 98)	150,774	347,271	Approx 460,000 (July 97)	VODR Approx 67,000		
4. Proportion of total licence holders	56.13 % (21 Nov 95)	36.4 % (June 98)	49.7 %	41.87 %	35 %	2.19 % Licence holders 3063224		
5. Trend analysis	"Increasing"			No access to historical data. No system in place to monitor future trends.	Slow increase, monitored by coordinators			

Attachment 6.

Attachment 7.

Donor Action Working

Among the many organizations working to alleviate the organ shortage, three in particular have committed to work together.

They are:

- Eurotransplant International Foundation, which has spearheaded the European Donor Hospital Education Programme (EDHEP), a programme to provide health professionals with the communications skills to make the donor request;

- Spain's Organización Nacional de Trasplantes (ONT), which has been particularly successful in increasing organ donation rates in Spain through support programmes for transplant coordinators; and,

- The Partnership for Organ Donation in the U.S., which has developed methodologies and tools to analyze and improve the donation process.

While these organizations have somewhat different goals and responsibilities, they have a shared commitment to alleviate the organ donation shortage. As a result, these experts formed a Working Group to review obstacles in the donation process, identify effective solutions and develop an international programme to help hospitals establish or improve standards of practice in organ donation.

The programme, called Donor Action, integrates the experience, expertise and activities developed by these organizations into materials to improve the donation process and bring about a focused effort to alleviate the organ shortage.

November, 1995

Introduction

During the last decade tens of thousands of people's lives have been saved, or their quality of life transformed, by transplantation. However, many patients continue to die because organ supply does not meet waiting list numbers.

While several organizations are actively considering ways to improve the donation rate, research shows that hospitals are missing a large potential for organ donation. Studies confirm that hospitals can achieve measurable improvements in the number of organ donors when an optimal organ donation process is in place.

Donor Action, an international programme to improve organ donation rates, is designed to optimize the hospital process so that all potential donors are identified. The programme also emphasizes a caring and sensitive approach to potential donor families in bringing up the subject of donation and the donation request.

This document is an invitation for hospitals to participate in the Donor Action programme to establish or improve donation practices in their hospitals.

The Opportunity to Improve the Donation Situation

With more than 60,000 people in Europe and the U.S. currently on waiting lists to receive organs for transplantation and the actual number of donors plateauing in many countries, the need to alleviate the organ shortage is immediate.

In 1994, experts from three organizations, Eurotransplant International Foundation (The Netherlands), Organización Nacional de Trasplantes (Spain) and The Partnership for Organ Donation (U.S.A.), collaborated to form a Working Group committed to improving organ donation rates and thereby helping to alleviate the organ shortage.

The Group reviewed all possible areas affecting the donor situation, including the numbers of potential donors; gaps or obstacles in the donation process; the attitudes, skills base and responsibilities of medical professionals involved in donation; hospital policies and procedures; as well as public perception of organ donation and transplantation.

The review revealed that the average hospital misses as many as one third of its potential donors because it lacks a clear process for organ donation. These potential donors are missed primarily because patients are not identified as potential donors and families are not presented with the option of donation.

The Working Group therefore decided to focus efforts on the development of a programme to assist hospitals in improving the donation process. Experience from both Spain and the U.S. confirms that consistent use of an optimal organ donation process can lead to a dramatic increase in donation.

The Donor Action programme ensures that potential donors are identified and that their families are asked about donation in a sensitive and caring manner. This, combined with ongoing training and support of the medical and nursing professionals involved, will effectively improve the donation situation.

Defining "Donor Action"

The ultimate goal of Donor Action is to positively affect organ donation rates. Programme materials have been designed for easy adaptation to meet diverse national and hospital needs, regardless of language or cultural differences.

To ensure that the materials are effective and appropriate, a number of pilots are underway in Europe to test and refine the materials. Other pilots are anticipated in North America.

These hospital partners piloting the programme are instrumental in ensuring the development of an optimal programme to effect measurable improvements in organ donation locally, nationally and internationally.

The Programme

The Donor Action materials comprise a module to establish a Donor Action Committee, a diagnostic review module, core implementation modules and a supplementary training and support programme for medical and nursing professionals.

Donor Action Committee Module

The Donor Action Committee is a hospital-based multi-disciplinary team with overall and ultimate responsibility to drive the Donor Action programme forward.

Diagnostic Review

A careful diagnosis is a critical first step in improving donation. The diagnostic review evaluates the specific hospital situation regarding donation rates, policies and attitudes. The results are used to help hospitals understand their potential for organ donation and subsequently determine which programme modules should be used to meet their needs.

Donor Action Modules

The Donor Action core modules provide comprehensive tools, resources and guidelines to improve specific hospital mechanisms for donor detection, organ donation and communication with donor families.

Training and Support Programme

A supplementary training and support programme offers training opportunities in such areas as communication skills, interviewing skills and media skills. It also serves as a reference for support services such as counselling.

Since not all hospitals will need the total Donor Action programme, the core modules are designed so that each module can stand alone. This format provides added flexibility to meet the varied requirements of individual hospitals.

Benefits to the Hospital

Donor Action provides hospitals with the opportunity to improve donation practices in their own institution and establish the hospital as a leader in improving donor rates locally and internationally.

Other benefits to participating hospitals are to:

- optimize existing hospital systems and promote increased effectiveness and efficiency in donation processes;
- concentrate responsibility for the donation process in the hands of a small number of highly-trained and motivated hospital staff;
- improve the care provided to families of potential donors;
- minimize staff uncertainty and anxiety in donation cases by establishing clear roles and responsibilities in the donation process;
- foster teamwork among medical professionals and build on the motivation of each professional involved;
- support the hospital's dedication to saving lives and improving quality of life.

The Donor Action programme also provides each hospital with the opportunity to routinely evaluate the effectiveness of its donation systems and procedures, and help measure their impact on improving organ donation rates.

The Hospital Commitment

Like any change process, the Donor Action programme involves an investment from each hospital both on an institutional and individual level.

The multi-disciplinary Donor Action Committee is established to initially assist with the diagnosis of the donation situation and educate relevant hospital professionals about the hospital's commitment to improving donation rates. Following diagnosis, the Committee is responsible to determine which Donor Action modules are used, guide the implementation of these modules, monitor progress and measure improvements in donation rates.

The core programme modules require support from hospital professionals directly involved in the donation process. This support is needed to ensure consistent, high-quality implementation of the established donation practices.

Donor Action is an initiative of Eurotransplant International Foundation (The Netherlands), Organización Nacional de Trasplantes (Spain), and The Partnership for Organ Donation (U.S.). The Initiative is facilitated by Rowland Healthcare and supported by Sandoz Pharma.

Further information is available from:
Rowland Healthcare, Fraumünsterstrasse 25, 8001 Zurich, Switzerland.
Tel. +41.1.212 56 00; Fax +41.1.212 55 61.

November, 1995

DONOR ACTION

A Call To Action

Presenting Donor Action

This manual has been compiled to help countries in their decision to adopt Donor Action and provides a guide to Donor Action National Working Groups on the adaptation of the materials to suit national needs and the nationwide implementation of the programme.

For further information please contact:

Donor Action Secretariat
Box 54 Addenbrooke's Hospital
Hills Road
Cambridge CB2 2QQ
United Kingdom

Tel/Fax: + 44 (0)1223 216 047

DEVELOPMENT

The critical shortage of donor organs is the single most important limitation to saving lives and transforming quality of life through transplantation. Among the many organizations working together to alleviate the organ shortage, three in particular have committed to work together.

EUROTRANSPLANT (NL), which has spearheaded the implementation of the European Donor Hospital Education Programme (EDHEP), a programme to provide health professionals with the communication skills to make a request for organ donation.

Spain's **ORGANIZACIÓN NATIONAL DE TRASPLANTES (SP)**, which has been particularly successful in increasing organ donation rates in Spain through support programmes for transplant coordinators.

THE PARTNERSHIP FOR ORGAN DONATION (US), which has developed methodologies and tools to analyse and optimize the donation process.

These three organizations form the international Donor Action Core Working Group.

The objectives of the Donor Action programme are to affect positively organ donation rates by helping hospitals establish or improve standards of practice in the organ donation process. Tools, resources, guidelines and skills are provided to assist hospitals to set up mechanisms to:

* Analyse the hospital's existing donation practices
* Identify specific areas for improvement
* Put in place appropriate Donor Action modules
* Provide training for key individuals
* Monitor and measure progress

THE DONOR ACTION PROGRAMME

The Donor Action programme materials comprise guidelines on how to establish a hospital Donor Action Committee, a diagnostic section, core programme modules and supplementary professional training and support. The core modules are designed so that each can stand alone or for use as an integrated package. Each includes training elements. This format provides flexibility to meet the varied requirements of individual hospitals.

DONOR ACTION COMMITTEE

The Donor Action Committee is a hospital based multi-disciplinary team with overall and ultimate responsibility to drive the programme forward.

DIAGNOSTIC SECTION

The diagnostic section evaluates the specific hospital situation regarding the donation rates, policies and attitudes. The results are analysed and used to help hospitals understand their potential for organ donation and subsequently determine which programme core modules should be used to meet their needs.

DONOR ACTION CORE MODULES

The stand alone core modules provide comprehensive tools, resources, guidelines and training workshops to improve hospital mechanisms for:

* Donor detection
* Donor referral
* Family care and communication
* Donor maintenance
* Organ retrieval

SUPPORT PROGRAMME

This supplementary programme serves as a reference for relevant support services.

CONTENTS

1. *STEPS TO THE NATIONAL IMPLEMENTATION OF DONOR ACTION*

* Form a multi-disciplinary Donor Action National Working Group. Existing EDHEP national Working Groups will provide an ideal basis for the Donor Action National Working Group.

* Set up the first Working Group meeting.

* Invite representatives from the Donor Action Core Working Group to present the Donor Action programme materials.

* Select Donor Action national Working Group members and national trainers to attend training courses.

* Review and adapt the Donor Action materials.

* Organize regional or individual hospital pilot evaluations before implementing the programme nationwide.

2. *COMPOSITION OF DONOR ACTION NATIONAL WORKING GROUP*

To ensure that decisions are made and the work gets done it is suggested that you create a National Working Group of 4 to 6 members. Consider coopting extra help as and when appropriate.

The ideal Working Group could comprise members of the following national organizations:

* Transplant societies
* Intensive care/neurosurgical societies
* National medical/nursing associations
* Transplant Coordinators organizations
* National Health Service
* National Organ Exchange Organization
* Organizations providing funding support

3. *FUNCTIONS OF THE DONOR ACTION NATIONAL WORKING GROUP*

The responsibility for the national adaptation and implementation of Donor Action rests with the Donor Action National Working Group. The group must, therefore, be well motivated and be prepared to devote time and energy to the project.

It is sensible to create a coordinator within the Working Group who can take overall responsibility for the allocation of the tasks among the Working Group, monitor the completion, presentation and quality of the translated material and the organization of the pilot hospital evaluations.

The tasks of the Donor Action National Working Group are as follows:

* To meet regularly and set deadlines
* To define responsibilities for each Working Group member
* To identify suitable Donor Action trainers
* To develop and implement training programmes
* To exercise budget control
* To consider appointing a full-time individual to manage the pilot evaluations and national implementation of Donor Action
* To record and analyse national data

Outline of Anticipated Costs to be Considered

* Working Group member travel costs
* Translating written materials
* Adapting/creating written and audiovisual materials to meet local needs
* Training programmes

4. *DONOR ACTION TRAINING COURSES*

Three phased, English language, training courses are organized and run by the Donor Action Core Working Group.

The courses are targeted at National Working Group members and future Donor Action trainers.

See Appendix 1 for description of the three training courses.

It is essential that all participants are familiar with the contents of the Donor Action Programme before attending the courses.

The main objectives of the training courses are as follows:

* To ensure a familiarity with the Donor Action programme goals and materials.

* To provide national trainers with skills to educate local trainers or hospital professionals, to introduce and implement the Donor Action programme.

* To establish a close dialogue between Donor Action National Working Groups and the Donor Action Core Working Group.

Following the courses any further assistance and guidance required by the national Working Group will be provided by the Donor Action Core Working Group.

5. *DONOR ACTION TRAINERS*

Three of the five Donor Action Core Modules contain training workshops:

* Donor detection
* Donor management
* Family care and communication

Designated Donor Action workshop trainers will have the opportunity to participate in the training courses under the guidance of the Donor Action Core Working Group.

National trainers will have access to the international Transplant Procurement Management Courses. For further information please contact the Donor Action Secretariat

Suitable Donor Action trainers can be found among:

* Anaesthesiologists.
* Transplant coordinators.
* Educational psychologists.
* Communication skills training experts.

6. *ADAPTING THE DONOR ACTION MATERIALS*

All the original programme materials are produced in English. This section provides some guidance on adapting Donor Action to meet local needs while keeping the original identity and content of the programme intact. These guidelines are based on of five years experience with the EDHEP programme (1991), which has been adapted for use in over 30 countries.

1. Donor Action has an identity

The following items aim to preserve Donor Action's origins and identity and should be included in local programmes.

* Donor Action logo and colours

* Donor Action stationary, information packs, programme manuals and teaching materials

2. Adapting Donor Action to meet local needs

* Credit authors and their institutions, identify translators

* Include logos of supporting organizations

* Use the name "Donor Action" or a close translation

* Develop separate local materials to promote Donor Action

3. The Donor Action materials to be translated/adapted

* The programme manuals and tools

7. *DONOR ACTION AGREEMENT*

In countries wishing to adopt and implement Donor Action a representative from a recognized organization will be asked to sign an agreement with the Donor Action Core Working Group, the holders of the copyright.

The purpose of the agreement is to preserve the quality of the programme during it's adaptation and implementation and to ensure that adequate help and guidance is provided by the Donor Action Core Group.

8. *APPENDIX 1. Content of Donor Action Training Courses*

1. Training Course One: Introduction to Donor Action and Diagnostic Phase
Duration: one day

Objectives
Participants become familiar with the reason for Donor Action and the purpose and content of the programme
Participants understand how to conduct and analyse the Medical Record Review and the Hospital Staff Survey
Case studies

2. Training Course Two: Donor Action Module Implementation
Duration: one day

Objectives
Participants become familiar with the purpose and content of the Programme Modules
Participants understand the steps involved in the introduction of each module
Case studies

3. Training Course Three: Donor Action Practical Skills
Duration: three one day courses

Objectives
Participants learn to run training workshop on donor detection skills
Participants learn to run training workshops on donor maintenance skills
Participants learn to run training workshops on family/communication skills

National trainers will have access to the international Transplant Procurement Management Courses. For further information please contact the Donor Action Secretariat.

Donor Action Programme

Contents

The Donor Action materials comprise a module to establish a Donor Action Committee, a diagnostic review module, core programme modules and a supplementary training and support programme for medical and nursing professionals.

Donor Action Committee

Initially, a hospital-based Committee is formed to lead the diagnostic review of hospital donation potential and to recommend specific priority areas to be improved. Based on the diagnosis, this Committee determines the Donor Action modules appropriate for their specific institution. The Committee also has the mandate to motivate relevant hospital staff to action.

Members of the Committee include a core group of key administrative and medical professionals as well as representative(s) from the Transplant Team, such as the Transplant Coordinator (TC).

Once specific Donor Action modules are put in place, the Committee assists in concentrating responsibility for their implementation. A Link Coordinator is identified as the in-hospital partner for the Transplant Coordinator and is responsible for the Donor Action programme in the hospital.

Diagnostic Review

Medical Records Review

The Medical Records Review (MRR) examines selected death records to assess the number of potential vs actual organ donors in the hospital; reviews the actions taken with each potential donor; and, helps identify specific areas for improvement. Data from the MRR is used to tailor the Donor Action programme to the particular hospital.

Hospital Attitude Survey

The Hospital Attitude Survey complements the Medical Records Review by assessing the hospital staff's attitudes, beliefs and knowledge of donation and transplantation.

Programme Tailoring

This unit guides the development of a hospital's own Donor Action programme. It collates and analyzes data collected from the Medical Records Review and the Attitude Survey to create a picture of the hospital's organ donation practices and determine the specific programme modules to be implemented in the hospital.

Donor Action Modules

Awareness Workshop

The Awareness Workshop generates understanding of organ donation issues and the need for improved hospital policies and procedures. It introduces the Donor Action programme and helps generate broad support for the programme within the hospital.

Module 1
Donor Detection

This module provides the tools to improve donor detection. It helps clearly define roles and responsibilities of the Link Coordinator(s) and other medical professionals involved.

Module 2
Donor Referral

This module provides the tools to ensure that identified potential donors are referred to the Transplant Coordinator. It also clarifies the roles and responsibilities of hospital staff, Link Coordinator(s) and the Transplant Coordinator.

Module 3
Family Care and Communication

This module has two aims:

- helping professionals meet the communication needs of the potential donor family; and,
- equipping medical professionals with skills to support bereaved relatives.

It also provides professionals with tools and skills training to ensure that families understand the concept of brain death and are offered the option of donation in a sensitive and caring manner.

Module 4
Donor Maintenance

This module acts as a resource file for optimal donor maintenance practices and recommends roles and responsibilities for medical professionals involved.

Module 5
Donor Organ Retrieval

This module provides a resource file of protocols and procedures to ensure optimal organ retrieval.

Training and Support

Component 1
Training and Educational Opportunities

This module provides skills training opportunitites to Transplant Coordinators and relevant hospital professionals in the areas of presentation, interviewing, interpersonal and media skills, as well as medical skills related to organ donation. It also provides examples of different communications situations as reference points for actions and reactions.

Component 2
Resource Directories

A resource file of training opportunities to improve, for instance, medical skills related to organ donation. It also includes a directory for counselling and other support structures to medical professionals in the sensitive areas surrounding organ donation and dealing with bereavement.

Donor Action is an initiative of Eurotransplant International Foundation (The Netherlands), Organización Nacional de Trasplantes (Spain), and The Partnership for Organ Donation (U.S.). The Initiative is faciiitated by Rowland Healthcare and supported by Sandoz Pharma.

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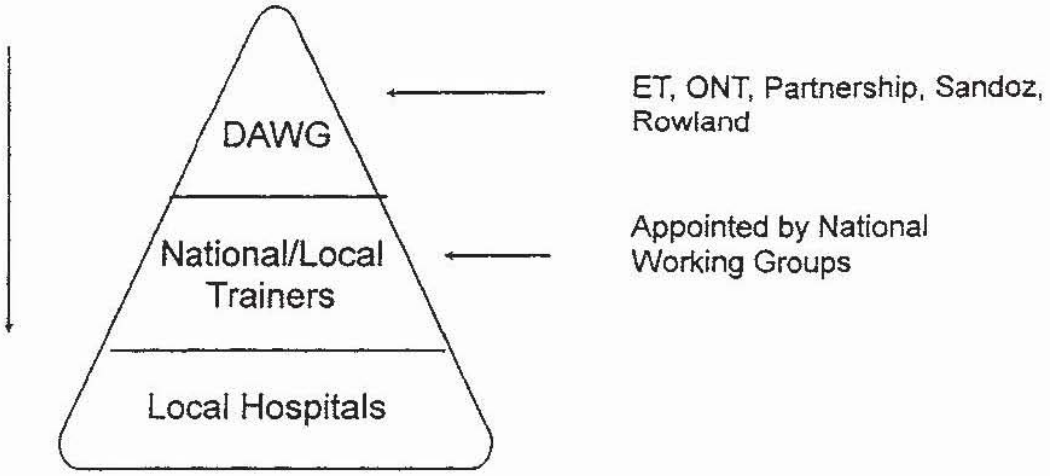
Rowland Healthcare, Fraumünsterstrasse 25, 8001 Zurich, Switzerland.
Tel. +41.1.212 56 00; Fax +41.1.212 55 61.

November, 1995

Donor Action TTT Workshops

Workshops 1 & 2 - Donor Action Programme



Workshop 3 - Practical Skills