



A Strategy for improving Organ and Tissue Donation in South Eastern Sydney

1999 - 2002

South East Health



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Good Health Care

Better Health

**A Strategy for improving
Organ and Tissue Donation in
South Eastern Sydney**

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Prepared by Jane Treloggen with the support of the South East Sydney Area Health Service Organ and Tissue Donation Liaison Committee:

Committee Members

Dr Ian Rewell	- Chair, Executive Director Sydney/Sydney Eye Hospital
Dr Lynette Lee	- Director Clinical Services South East Health
Ms Kerri Carlton	- Australian Cord Blood Bank
Ms Jill Davidson	- Social Work Dept. St George Hospital
Ms Sally Willis	- Lions NSW Eye Bank
Ms Belinda Lee	- NSW Bone Bank
Mr Kuet Sin Le	- Sydney Heart Valve Bank
Ms Michael McBride	- Executive Officer Tissue Banks South East Health
Prof. Frank Billson	- Director Lions NSW Eye Bank
Dr Theresa Jacques	- Director ICU St George Hospital
Ms Annemarie Kaan	- Transplant Coordinator St Vincent's Hospital
Ms Jo Mitchell	- Director Health Promotion South East Health
Dr Nick Coroneos	- Director ICU Prince of Wales Hospital
Dr Neil Kiloh	- ICU Sutherland Hospital
Mr Michael Walsh	- Ethicist
Dr Gad Kainer	- Dept. Nephrology Sydney Children's Hospital
Dr Bob Wright	- Director ICU St Vincent's Hospital
Prof. Bruce Pussell	- Dept. Nephrology Prince of Wales Hospital
Dr Barry Duffy	- Director ICU Sydney Children's Hospital
Ms Susan Taylor	- South East Health Learning Service
Mr Don McFadden	- Donor Dad
Mrs Colleen McFadden	- Donor Mum
Ms Jane Treloggen	- South East Health Organ and Tissue Donor Coordinator

September 1999

Copies of this document can be obtained from:

Clinical Services, Policy and Planning Unit
South East Health
P.O. Box 430
Kogarah NSW 1485

Phone (02) 9382 9831
or

Visit our Intranet site on <http://sesinfo/cspp/publications/publications.shtm>

Foreword

For many Australians and particularly residents of South Eastern Sydney, the best or the only hope of life may be the receipt of an organ or tissue for transplantation from another person. Australia has an extremely low rate of organ and tissue donation compared with other countries. This is despite a very high surveyed rate of willingness to donate.

Federal and State policies have been developed to increase awareness of donation and increase actual donation rates. At a local level the formation of the South East Health Organ and Tissue Donation Liaison Group has been a response to these initiatives.

The Area Committee on Organ and Tissue Donation has developed strategic goals for improvement in Organ and Tissue donation rates of residents of South Eastern Sydney and for hospitals in the Area facilitating donation. These goals are in keeping with national and statewide policies. It is pleasing to note that preliminary data has revealed a recent increase in the numbers of multi-organ donors in the hospitals within our Area. The Area is committed to work towards increasing donation rates to levels comparable to National and International standards.

I am pleased to commend this plan for improving the health of fellow Australians.



Deborah Green
Chief Executive Officer

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1. EXECUTIVE SUMMARY

In Australia the actual number of transplants performed annually has increased for all types of organs and tissues; however, many more people could benefit from the life saving procedures if sufficient organs and tissues were available.

The Mission Statement of the South East Health Organ and Tissue Donation Liaison Committee is;

To improve Organ and Tissue Donation within the South East Health Area, ensuring dignity for all concerned.

The rate of multi-organ donations in South Eastern Sydney has been approximately 13 donors per million population for many years; higher than the national average, but lower than that of South Australia. In 1998 it rose to 19.9 per million. National and State studies suggest that the rate of potential donors is approximately twice that of the actual rate and that there are strategies that could be employed to improve those figures.

The initiative of the Australian Red Cross Blood Service NSW to form a network to address the deficiencies in donation rates began one year ago. South East Health is participating in statewide activities and has adopted the following goals for organ and tissue donation:

- ◆ Improved community awareness of Organ and Tissue Donation.
- ◆ Increased awareness within the health community of Organ and Tissue Donation.
- ◆ Improve collection of organ and tissue donation performance measures.
- ◆ Improve Organ and Tissue Donation processes in South East Health Hospitals.

A diverse range of initiatives will be implemented to achieve these goals. The four key indicators of progress will be:

- ◆ Annual increase in positive consent indication on driver's licences in South Eastern Sydney postcodes for organ and tissue donation,
- ◆ Increase in consent for donation.
- ◆ Decrease in missed potential donors in South East Health hospitals
- ◆ Decrease in missed potential organs due to failure to maintain organ function

2. INTRODUCTION

Following a review of practices in 1996, the Australian Red Cross Blood Service (ARCBS) - NSW identified some of the major issues that impede organ and tissue donation and submitted a plan for improving the donor rates to the NSW Health Department.

The response from the Health Department, announced on the 6th June 1997, included a financial grant. This has resulted in the establishment of a centrally based facility, the NSW Co-ordination Centre for Organ and Tissue Donation (CCOTD), located at the Red Cross Blood Transfusion Service, and an Area Health Service Network to improve organ and tissue donation rates in NSW. In addition, support for existing bereavement services for organ donor families is planned.

More than 80% of donors are cared for by Intensive Care Units (ICU'S), the majority of these being within metropolitan Area Health Services (AHS) in NSW. The remaining donors are equally spread amongst the smaller district and base hospitals. Nine AHS's have been identified with the greatest potential for organ donors through their provision of critical care medicine, specialist neurosurgical services, trauma and retrieval services, and a networking relationship with rural services. South East Health is one of those Areas. (Fig 1.)

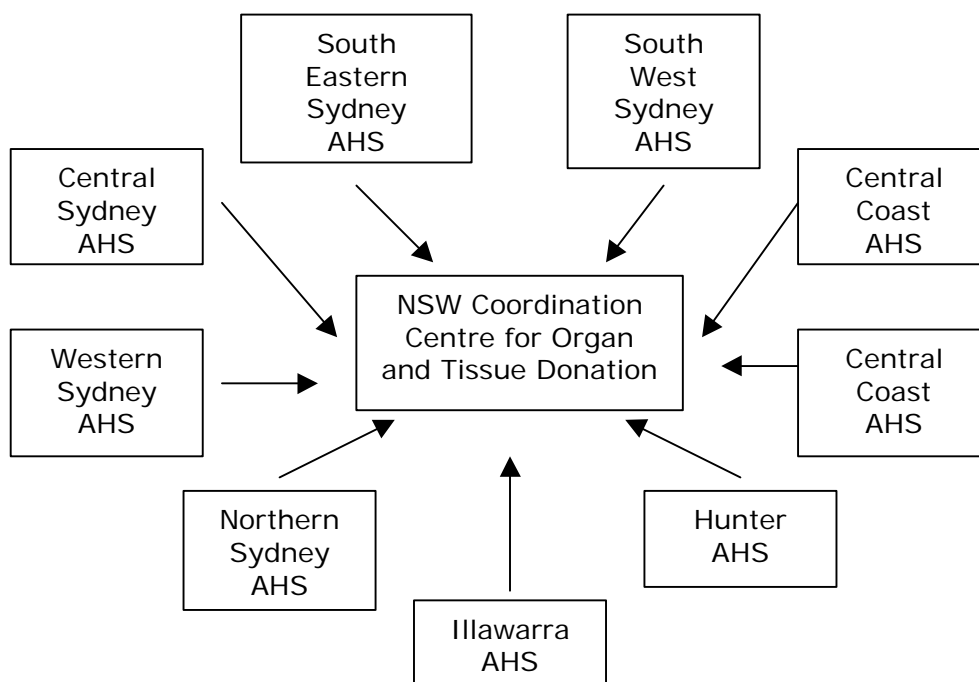


Figure 1. Area Health Services with potential for Organ and Tissue Donation

Each of these AHS have signed a performance agreement with the NSW Co-ordination Centre for Organ and Tissue Donation that details the funding and the creation and support of the AHS network. Initiatives include the appointment of an Area Donor Coordinator and formation of an Area Organ and Tissue Donation Liaison Group. The performance agreement also commits the Area to support the *Plan for Maximisation of Organ and Tissue Donation* by

the ARCBS - NSW/ACT. This document should be read in conjunction with this strategic directions statement.

3. THE OPERATING ENVIRONMENT

Demography

- ◆ South East Health (SEH) encompasses the Local Government Areas of Sutherland, Hurstville, Kogarah, Rockdale, Randwick, Botany, Waverley, Woollahra and approximately 60% of South Sydney and Sydney City.
- ◆ SEH is the second most populous Area Health Service in NSW:-

TABLE 1: ESTIMATED RESIDENT POPULATION FOR NSW AREA HEALTH SERVICES, 1997

Area Health Service	Population
Northern Sydney	755 929
South Eastern Sydney	749 038
South West Sydney	741 736
Western Sydney	652 566
Hunter	525 758
Central Sydney	476 870
Illawarra	338 859
Wentworth	304 993
Central Coast	275 427
Greater Murray	257 502
Northern Rivers	253 370
Mid North Coast	253 181
Southern NSW	181 046
New England	177 879
Mid Western	166 396
Macquarie	103 255
Far West	49 386

Data Source: NSW Health Department

- ◆ Population projections from the NSW Dept. of Health for the Area predict 772,660 residents in the year 2001, and 801,760 in the year 2006.
- ◆ Nearly 25% of residents over 5 years of age within SEH speak a language other than English at home. This compares with 18% for NSW. These languages are; Chinese (4.5%),

Greek (4.3%), Arabic (2.1%), Italian (1.8%), Macedonian (1.3%), Spanish (1.2%) and Russian (0.9%). (Figures taken from SESAHS Population health profile 1997).

- The major cause of death for South East Health residents for the period 1991 – 1995 was disease of the circulatory system, which includes ischaemic heart disease and stroke. Cancer, diseases of the respiratory system and injury/poisoning were also major causes of mortality.

Facilities

- ◆ South East Health has eleven hospitals within its boundaries:
 - Three principal teaching hospitals:- Prince Henry/Prince of Wales, St George, St Vincent's.
 - Three specialist hospitals:- Royal Hospital for Women, Sydney Children's Hospital, Sydney/Sydney Eye Hospital.
 - District hospital:- Sutherland Hospital
 - Two palliative care facilities:- Calvary Hospital, Sacred Heart Hospice
 - Two aged care facilities:- War Memorial Hospital, Garrawarra Centre for Aged Care
- ◆ Within the boundaries of SEH are sixteen private hospitals with approximately 1,300 licensed beds, and twenty-two nursing homes and hostels with approximately 4,000 licensed beds.
- ◆ The Area has Intensive Care beds at St Vincent's, St George, Prince of Wales, Sutherland and Sydney Children's Hospitals. It performs renal transplantation at Prince of Wales, St Vincent's and St George Hospitals, and heart and heart/lung transplantations at St Vincent's Hospital.
- ◆ The Area hosts four Tissue Banks – the Lions NSW Eye Bank at Sydney Eye Hospital, the NSW Bone Bank at St George, the Sydney Heart Valve Bank at St
- ◆ Vincent's and the Australian Cord Blood Bank at the Royal Hospital for Women and Sydney Children's Hospital.

4. ORGAN AND TISSUE DONATION WITHIN THE SOUTH EAST HEALTH AREA

Australia has a policy based on the “opt in” system of organ donation. This means that an individual may choose to donate organs or tissue upon death and make this decision known before death. It is felt that the most important step in increasing the rate of donation in Australia is to foster family discussion on the topic, as relatives will be asked for permission after death.

When donation rates in Australia are compared with those of other countries, Australia has the lowest rate of 10.3 per million of population (pmp), which is the historical and universal measure for donor rates. This compares with the highest rate in Spain of 29 pmp. (Table 2.)

TABLE 2: INTERNATIONAL DONOR STATISTICS, 1997

Country	Euro-Trans	France	Italy	Spain	Port	Scan	UK	USA	Can	Aust
Donors pmp	14.5	15.0	11.6	29	20.5	13.5	14.5	20.6	14.5	10.3

Eurotransplant – Germany, Austria, Belgium, Luxembourg, The Netherlands

Scandia Transplant – Denmark, Finland, Norway, Sweden

Data Source: Council of Europe 1998

At a national level, the number of multi-organ donors - actual and per million of population has fallen in 1997 in comparison to 1996, despite an increase in population size. (Table 3.)

TABLE 3: NUMBER OF DONORS AND RATE PER MILLION OF POPULATION BY STATE AND TERRITORY

State	Population	1996		1997		
		Actual Donors	Donors pmp	Population	Actual Donors	Donors pmp
NSW/ACT	6 512 000	69	10.6	6 584 200	69	10.5
VIC/TAS	5 036 000	50	10.0	5 078 600	47	9.2
QLD	3 339 000	35	10.5	3 401 200	37	10.9
SA/NT	1 656 000	28	17.0	1 666 900	29	17.4
WA	1 766 000	12	6.8	1 798 100	8	4.4
Australia	18 309 000	194	10.6	18 529 200	190	10.3

Data Source; 1997 Report – Organ and Tissue Donation and Transplantation NSW/ACT

These low donor rates are reflected in the high organ waiting lists in Australia and the number of patients transplanted. (Tables 4&5.)

TABLE 4: ORGAN WAITING LIST, JANUARY 1999

Organ/tissue	NSW/ACT	Australia
Kidney	720	1459
Liver	23	57
Heart	52	87
Heart/lung	6	10
Lung	25	64
Pancreas	12	34
Cornea	400	

Data Source: Australians Donate

TABLE 5: PATIENTS TRANSPLANTED IN 1998

	NSW/ACT	Australia
Organ donors	65	196
Donors per million pop	10	10.5
Kidney	156	502
- cadaveric	130	358
- live	26	144
Liver	52	154
Heart	26	72
Heart/Lung	4	4
Lung	18 double, 9 single	83
Pancreas	14	18
Cornea	450	
Bone	119	1623

Data Source: ANZDATA

NSW/ACT has the highest actual donor rate, but because it has the largest population, the donation rate (pmp) is just above the national rate. It falls below those of Queensland and SA/NT.

Actual donors and numbers per million of population have improved in the South East Health Area. (Table 6.) Given the size of the population and the age

demographic, the South East Health Area represents a good opportunity to show further improvement.

TABLE 6: SOUTH EAST HEALTH ACTUAL MULTI-ORGAN DONORS

Year	1990	1991	1992	1993	1994	1995	1996	1997	1998
Actual Donors	12	15	11	11	12	6	10	10	15
Donors pmp							13.8	13.3	19.9

Hospitals included: St Vincent's, St George, Prince of Wales, Sutherland, Sydney Children's and St Vincent's Private

5. THE ORGANISATION OF ORGAN AND TISSUE DONATION IN THE SOUTH EAST HEALTH AREA

An area wide coordinated approach to organ and tissue donation, involves multidisciplinary participation from a range of professionals and facilities.

Hospital Staff

Hospital staff directly facilitate organ and tissue donation for transplantation. It is the skilled and committed people working in our hospitals who fulfil the wishes of the deceased and their families. These people are critical in the organ and tissue donation process, which is a community service to the population of the SEH, the State and indirectly to the other States of Australia.

Area Donor Coordinator

The main functions of this position are to coordinate and facilitate the process of organ and tissue donation. To act as a resource for the promotion of and education about organ and tissue donation within the hospitals, and local community of the SEH, and to assist with the follow up of Donor families. Collection of data for the Australasian Organ Donor Database.

Area Liaison Group

An Area Organ and Tissue Donation Liaison Committee has been established in accordance with the Health Service Network Plan with the aims of providing effective review and an accountability structure for organ and tissue donation activities locally and the Area Donor Coordinator.

The South East Health Area Liaison Group has amongst its members a representative from each ICU, Coordinators from each Tissue Bank, Social Work, Transplant Unit, Ophthalmology and Nephrology units, Health Promotion, and an Ethicist, the Area Executive and a Donor Family.

Area Education Working Party

This group has been established to be a sub committee to the Liaison Group with special emphasis on the educational requirements of the Area.

State Liaison Committee

The Chairman of each Area Liaison Group makes up the State Liaison Committee, which provides guidance to the Area Liaison Groups and is an avenue of feedback from the Medical Director of the State Coordination Centre.

Lions NSW Eye Bank

Situated at the Sydney/Sydney Eye Hospital, the Eye Bank is the centre for the storage, preparation and distribution of corneas in NSW and ACT. The Director and Coordinators are responsible for the coordination of the donation process, and for the approach to families for consent in tissue only donors - for corneas, bones and heart valves.

NSW Bone Bank

Established in 1994, the Bone Bank is situated at St George Hospital. It is responsible for the retrieval and storage of bone from cadaveric donors and patients under going joint replacement. Bone is distributed throughout NSW and the ACT.

Sydney Heart Valve Bank

Located at St Vincent's Hospital, the Heart Valve Bank coordinates retrieval of heart valves from cadaveric donors and suitable hearts removed from heart transplant recipients. For implantation in patients with heart valve defects and disease State wide.

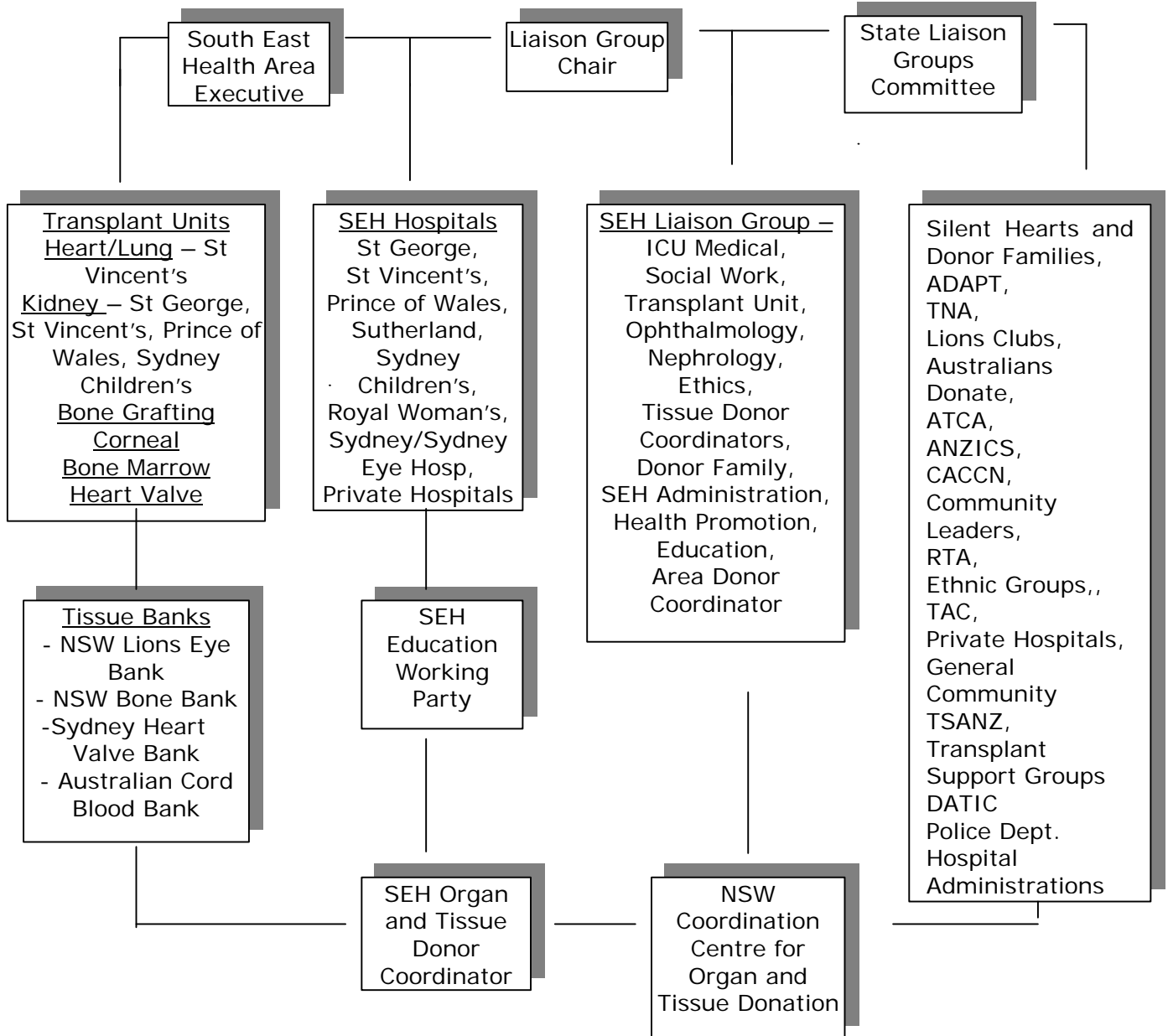
Australian Cord Blood Bank

Situated at Sydney Children's Hospital, the cord blood bank collects stem cells from the blood in the umbilical cord and placenta immediately after birth. Distribution of cord blood for the treatment of leukaemia is worldwide.

The functional relationships between the key groups and agencies involved in organ and tissue donation are described in Figure 2.

**FIGURE 2. SOUTH EAST HEALTH AREA ORGAN AND TISSUE DONATION
FUNCTIONAL RELATIONSHIPS**

Improving Organ and Tissue Donation



- ADAPT – Australasian Donor Awareness Program
- TNA – Transplant Nurses Association
- ATCA – Australasian Transplant Coordinators Association
- ANZICS – Australian and New Zealand Intensive Care Society
- CACCN – Confederation of Australian Critical Care Nurses
- RTA – Roads and Transport Authority
- TAC – Transplant Advisory Committee
- TSANZ – Transplant Society of Australia and New Zealand
- DATIC -- Donation and Transplantation Information Council

6. GUIDING PRINCIPLES FOR ORGAN AND TISSUE DONATION FOR SOUTH EAST HEALTH

Endorsed by the South East Health Organ and Tissue Liaison Group at the Strategic Planning Day 22nd February 1999.

- ◆ Human dignity at all levels will be respected. This includes the dignity of the prospective donor, the dignity of the prospective donor's family, and the dignity of the prospective recipient.
- ◆ Provision of care to the patient takes precedence over the interests of organ and tissue donation.
- ◆ The decision of a person about whether or not to donate organs and tissues is respected.
- ◆ The goal of organ and tissue donation is to benefit a recipient and the duty of all those involved is to protect the recipient as far as is reasonably possible, from harm.
- ◆ Recognition of the needs of health professionals involved in organ and tissue donation is also an application of the fundamental principle of respect for human dignity.
- ◆ Awareness of cultural sensitivity will be important in all aspects of the organ and tissue donation process.

7. IDENTIFIED GAPS IN SERVICE PROVISION

Acknowledged by the South East Health Organ and Tissue Donation Liaison Group on the Strategic Planning Day 22nd February 1999

To progress organ and tissue donation planning in a coordinated way the requirements are:

- ◆ **Community awareness** – there are myths surrounding organ donation which are a barrier to commitment and support. Specific areas include schools and the media.
- ◆ **Spiritual leadership awareness** - profiling and support is required.
- ◆ **Awareness in the Health community** - again, there are myths and beliefs amongst health staff, which prevent commitment and support.
- ◆ **Data** – there is very little available at present on numbers of potential donors, reasons for not becoming donors and organ specific issues.

8. THE WAY FORWARD

Mission Statement

To improve organ and tissue donation within the South East Health Area, ensuring dignity for all concerned.

Objectives for South East Health Organ and Tissue Donation

Goal: Improved community awareness of organ and tissue donation

Activities: Development of a community education strategy.

Participation in the South East Health - Health Kiosk located at Eastgardens shopping centre, and other health promotion opportunities provided by South East Health.

Linking with Coordination Centre for Organ and Tissue Donation state initiatives for promotion.

Establishment of strong links with Australians Donate, the national body for organ and tissue donation.

Establishment and maintenance of contact with Roads and Transport Authority (RTA), Motor Registry Branches including providing education opportunities for branch staff.

Support for initiatives for a National registry and linking of RTA data.

Establishment and maintenance of a relationship with Area General Practitioners.

Establishment of local media contacts and religious press.

Introduction and explanation of issues to members of local government.

Outcome: Annual increase in consent indication on drivers' licences in South Eastern Sydney postcodes for organ and tissue donation.

Goal: Increased awareness in the health community of organ and tissue donation

Activities: Appointment of Area Donor Coordinator.

Regular education sessions directed by Area Donor Coordinator.

Australasian Donor Awareness Programme (ADAPT) Workshops – for medical and nursing personnel, run within the Area.

Implementation of Australasian Organ Donor Database (AODD) at St George, St Vincent's, Sydney Children's, Sutherland and Prince of Wales Hospitals.

Review of QI tool (AODD) results by individual units and Area Intensive Care Committee meeting.

Identification of staff with difficulties with organ and tissue donation – counselling may be required by peers, ?exemption or formation of a roster for anaesthetic staff – discussion at Directors of Clinical Services meeting.

Outcome: Increase in the numbers of multi-organ donations in SEH hospitals and in the number of tissue donations.

Goal: **Improve collection and utilisation of organ and tissue donation performance.**

Activities: Conduct death/organ donation audit - AODD

Completed data gained from death audits in the past used as benchmark for current audit.

Review of the notification of deaths from Area hospitals to Lions NSW Eye Bank.

Advocacy for a change in legislation to mandate all cases of brain death being reported and acted on.

Seeking of support in regard to organ and tissue donation issues from Local, State and Federal members of Parliament.

Outcome: Increase in consent for donation. Decrease in missed potential donors in SEH hospitals. Decrease in missed potential donors due to failure to maintain organ function.

9. EVALUATION AND MONITORING

Internal and external evaluation and monitoring will be conducted to ensure progress of this plan's implementation. Internal evaluation of this strategic plan will take the form of an Annual report by the South East Health Organ and Tissue Donor Coordinator, which will address the activities and the outcomes detailed in the plan. The report shall be presented to the South

East Health Organ and Tissue Donation Liaison Group and in turn the Board of South East Health.

External evaluation will take the form of reporting quarterly to the Medical Director of the Coordination Centre for Organ and Tissue Donation – Australian Red Cross Blood Service NSW/ACT and annually to the State Liaison Group.

These formal mechanisms will assist in charting progress in achieving the goals of the service and in doing so provide the opportunity for enhanced quality of life for transplant recipients and their families.