The Bob and June Prickett Churchill Fellowship undertaken to investigate programs and strategies to increase organ donation and transplantation rates in cultural groups

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Signed: Lee Wood

Dated: 28 October 2012
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Executive Summary

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Project Description
The primary purpose of my Churchill Fellowship was to investigate programs and strategies used in the United States to increase organ donation and transplantation rates in cultural groups. A secondary benefit of my Fellowship was the opportunity to enhance my understanding of organ and tissue donation programs in the United States.

Highlights
- Spending time with the Family Services team at Legacy of Life Hawaii, recognising the passion for their work and the true meaning of the Aloha spirit.
- Meeting and learning about education strategies from the Los Angeles OneLegacy multicultural Media and Outreach team, and being taken to lunch at a truly traditional Mexican restaurant.
- The SIM centre experience at OneLegacy.
- Learning from the Community, Hospital and Donor Services multicultural team members at Life Alliance Organ Recovery Agency in Miami and enjoying my first experience of Haitian food.
- Meeting and learning from the enthusiastic Public Affairs and Community Education team at Washington Regional Transplant Community (WRTC).
- Whilst at WRTC, meeting Mary Ganikos, from the Education Branch, US Health Resources and Services Administration (HRSA) and hearing about HRSA's multicultural grants program.
- Being amazed at the rigour of WRTC's Recovery Services staff selection and training processes.
- Meeting and learning from the Marketing and Communications team at the New York Organ Donor Network (NYODN).
- Observing the comprehensive performance improvement and compliance activities undertaken at the NYODN.
- Meeting with Nancy Fahrenwald, Karla Abbott & the South Dakota Lions Eye & Tissue Bank staff, sharing our stories and realising, despite being thousands of miles apart, we share similar hopes and experiences.

Recommendations
- Increase the number of culturally and linguistically diverse (CALD) employees within the organ and tissue donation sector.
- Consider the use of trained CALD volunteers in consent conversations with CALD families.
- Expand multicultural volunteer networks both locally and nationally.
- Hold a national forum with key stakeholders focused specifically on identifying multicultural issues in the donation and transplantation field and strategies to address these.
- Implement a national day focused specifically on increasing awareness of donation issues in CALD communities.
- Move towards increased recognition of 'first person' consent in conversations with potential donor families.
- Continue with the implementation of an electronic donor referral system in Australia.
- Further the network of donor family and recipient volunteers and provide consistent training to these groups.

Implementation and Dissemination
- Present findings to colleagues at a local level.
- Utilise knowledge gained to further develop educational programs for Indigenous Australians, particularly in the Northern Territory.
- Present findings at national meetings to senior staff of the Australian Organ and Tissue Authority (AOTA), State Medical Directors and jurisdictional colleagues.
Introduction

In 2004, I commenced working in the field of organ and tissue donation as the solitary Organ Donor Coordinator for the Northern Territory (NT) within the NT Department of Health. In this role I supported donor families, coordinated organ donation cases, undertook professional education and community advocacy activities, as well as providing policy advice to government. Subsequent to the reform of Australia's organ and tissue donation sector in 2009, I commenced in the new role of Program and Policy Director of DonateLife NT. I now manage a team of seven staff, with oversight from the NT Medical Director for Organ and Tissue Donation.

During my time in the sector I have become acutely aware of the need for more organ donors in Australia, in order to provide life-saving transplants to those on transplant waiting lists. While Australia has made recent advances in increasing donor numbers through a coordinated national approach, a sustained effort is required to maintain and further increase the number of organs available for transplantation.

There is limited information available in Australia on strategies and programs that can assist to increase awareness and understanding of organ and tissue donation in culturally and linguistically diverse populations, and to encourage individuals in these populations to consider becoming organ and tissue donors. This is of particular significance in the Northern Territory where Indigenous Australians (who comprise one third of the NT population) are over-represented in the organ failure population group, and yet are under-represented in the transplant recipient group.

In 2008, I commenced a project to develop resources to educate Indigenous Territorians about organ and tissue donation. I worked in partnership with Indigenous transplant recipients, health organisations, a graphic designer and a film production company to produce a set of culturally appropriate educational resources, which are now being used both in the Northern Territory and across Australia.

In searching for further information on strategies and programs to assist in increasing organ donation and transplantation rates in culturally and linguistically diverse groups, I discovered a number of initiatives being undertaken in the United States.

My Churchill Fellowship has provided me with an opportunity to travel to the United States to learn more about programs and strategies used to effectively engage culturally diverse populations in order to increase donation and transplantation rates. I am very grateful for this opportunity and look forward to continuing to work in this very rewarding and beneficial field.

Acknowledgements

- First and foremost, I would like to acknowledge and sincerely thank Mr Bob Prickett, former Churchill Fellow and sponsor, without whose generous sponsorship this incredible opportunity would not have been possible. To the benefit of many Australians, Bob has sponsored a number of Fellowships relating to organ and tissue donation and transplantation.
I would also like to thank the Churchill Trust, and in particular the Northern Territory Regional Committee, for considering this a worthwhile project to be undertaken.

I would like to thank Ms Holly Northam, Assistant Professor of Critical Care Nursing at the University of Canberra, and a 2006 Churchill Fellow, for her encouragement to apply for this opportunity.

I would like to thank Associate Professor Dianne Stephens, NT Medical Director of Organ and Tissue Donation, as well as my fellow DonateLife NT colleagues, for their support, encouragement and commitment to this area.

I would like to thank my husband Peter and son Mark for accompanying me on this tour of the United States and providing great support over the six-week Fellowship period.

I met so many people during the 6 weeks of my Fellowship studies, all of whom showed the same dedication to their work and who I sincerely thank for their willingness to share information with me and for their kind hospitality. I was also grateful for the opportunities I was given to share information on organ and tissue donation in Australia, as well as being able to showcase resources developed in the Northern Territory.

Lastly, I would like to extend special thanks to the following people for their assistance in helping organise my Fellowship experiences in the United States:

- Felicia Wells-Williams, Legacy of Life, Honolulu, Hawaii
- Carla Hentz, OneLegacy, Los Angeles, California
- Yilian Fraga, Life Alliance Organ Recovery Agency, Miami, Florida
- John Ogden, Washington Regional Transplant Community, Annandale, Virginia
- Bethany Stout-Davie, New York Organ Donor Network, New York
- Nancy Fahrenwald, South Dakota State University, South Dakota
Programme

Week of 25-29 June 2012 – Legacy of Life, Honolulu - Hawaii

- Meeting with Felicia Wells-Williams, Family Services Director
- Quarterback meeting (Referrals and Case Review) with Family Services, Clinical Services & Hospital Development
- Meeting with Reverend Ruth Peterson, Family Services & Chaplain
- Meeting with Pam Thompson, Family Services
- Meeting with Mari Kanemura, Family Services
- Presentation to Legacy of Life regarding organ donation in Australia
- Meeting with Carol Anne Gordon, Family Services
- Meeting with Katherine Kickertz, Clinical Services Director
- Meeting with Barbara Southern, Marketing and Fund Development Director
- Meeting with Dustin Wright, Hospital Services
- Meeting with Enid Liua, Community Outreach
- Meeting with Gerry Estrella, Tissue Program Director
- Tour of the Hawaii Lions Eye Bank

Week of 2-6 July 2012 – OneLegacy, Los Angeles - California

- Meeting with Carla Hentz, Donation Development Specialist
- Meeting with Aaron Cohen, Manager Donor Referral and Allocation & Jesse Bravo, Manager Tissue Procurement
- Meeting with Matthew McCoskey, Supervisor Donor Allocation and Lori Serra, Donor Allocation Specialist
- Meeting with Diane Green, Manager Family Care Services
- Meeting with Elena De La Cruz, Media Relations Specialist
- Meeting with Sonia Navarro, Latino Community Development Coordinator and Sabrina Ho, DMV & Media Relations Specialist/Asian Community Development Coordinator
- Meeting with Luz Diaz, Clinical Aftercare Specialist
- Case work at a Los Angeles hospital with Kathleen Turner, Procurement Transplant Coordinator, Erik Arenas, Family Care Specialist & Stephen Hasty, Donation Development Coordinator
- Meeting with Maria Stadtler, Director Donation Science Research and Education
- SIM centre experience with Maria Stadtler and SIM centre staff: Rick Ash, Jenna Graciano, Laura Teasley and Melissa Legree
- Meeting with Michelle Post, Clinical Aftercare Specialist

Week of 9-13 July - Life Alliance Organ Recovery Agency (LAORA), Miami - Florida

- Meeting with Yilian Fraga, Manager Donor Services
- Meeting with Leslie Cortina, Executive Director
- Meeting with Susan Ganz, Medical Director
- Meeting with Karen Garcia, Director Community and Hospital Services
- Meeting with Rey, one of LAORA's referral responders
- Meeting with David Grant, Manager Preservation and Surgical Services
- Meeting with Rosetta Rolle Hylton, Communications Coordinator and Designated Requestor
- Meeting with Ken Trachy, Director Special Projects
- Meeting with members of the Quality Assurance team

**Week of 16-20 July 2012 - Washington Regional Transplant Community (WRTC), Annandale - Virginia**

- Meeting with John Ogden, Manager Public Affairs and Community Education
- Meeting with Bea and Debra from the Family Services team
- Meeting with Rhonda Griffin, Mary Delaney, Freddie Medina and John Ogden, Community Education
- Presentation to Washington Regional Transplant Community on organ donation in Australia
- Meeting with Elling Eidbo, Executive Director, Association of Organ Procurement Organisations
- Meeting with Jennifer M Porter, Attorney at Law
- Meeting with Mary Ganikos, Chief, Education Branch, Health Resources and Services Administration (HRSA), Department of Health and Human Services
- Meeting with Lisa Colaianni and Maureen Balderston, Donor Family Advocates
- Meeting with Darden Sachs, Manager of Recovery Services
- Meeting with Kenneth Boyd, Director of Hospital Services and Professional Education
- Meeting with Lori Brigham, Executive Director WRTC

**Week of 23-27 July - New York Organ Donor Network (NYODN), New York**

- Case review meeting - Clinical Services, Hospital Services & Quality Assurance team
- Meeting with Charles Gonder, Clinical Manager
- Meeting with Margaret Gallagher, Manager, Hospital Services
- Meeting with Kristin Delli Carpini, Manager, Organ Allocation
- Meeting with Lisa Seymour, Learning Specialist, NYODN
- Meeting with Luba Ashurov, Manager, Tissue Recovery & Veronica Fernandez, Manager, Donor Centre
- Internal Performance Improvement Committee (IPIC) meeting
- Meeting with Michael Goldstein, Medical Director, NYODN
- Meeting with Karin Statler, Manager, Hospital and Family Services
- Meeting with Julia Rivera, Angela Palmieri, Stefan Segadlo, and Karen Cummings, Marketing and Communications team
- Meeting with Natalie Benavides, Director Hospital Services
- Meeting with Ronnie Schwartz, Marie Colon, Donor Family Services Coordinator and Alicia Algeo, Manager, Donor Family Services
- Meeting with Jim Aranda, Chief Financial Officer
- Meeting with Julie Mirkin, Vice President Operations
- Meeting with Waheed Tajik, Director Performance Improvement & Corporate Compliance Officer
- Meeting with Linda Bowes, Director of Education and Training
- Meeting with Julie Mirkin, Vice President Operations
- Meeting with Helen Irving, Chief Executive Officer & President, NYODN

**Week of 30 July - 3 August - South Dakota State University & South Dakota Lions Eye & Tissue Bank**

- Meeting with Nancy Fahrenwald, Associate Dean Nursing Research & Associate Professor, South Dakota State University
- Tour of the South Dakota Lions Eye & Tissue Bank
- Meeting with Karla Abbott, Nursing Instructor at Augustana College, Sioux Falls and a member of the Cheyenne River Lakota Sioux tribe, Nancy Fahrenwald and South Dakota Lions Eye & Tissue Bank staff - Gail Ries, Director of Marketing and Development & Joan Hammond, Administrative Assistant
- Dual presentations regarding American Indian and Indigenous Australian organ donation education programs and the resources developed as part of these.
Background

Organ and Tissue Donation in Australia

Notable facts and information:

- Approximately 1,600 people are on Australian organ transplant waiting lists.
- In 2011, there were 337 deceased organ donors and 257 living organ donors resulting in 1296 organ transplants.
- Studies show 90% of Australians say they support donation.
- Services of Remembrance (in memory of organ donors) are held annually by each Australian state and territory.
- DonateLife Week is held annually in Australia in the last week of February.
- In February 2010, the DonateLife 'Book of Life' was released (this contains inspirational stories of people touched by organ and tissue donation).

The key pieces of legislation governing organ and tissue donation in Australia are:

- The Australian Organ and Tissue Donation and Transplantation Authority Act (enacted in 2008). This Act primarily allowed for the establishment of the Australian Organ and Tissue Donation and Transplantation Authority, and the establishment of its Advisory Council, and expert advisory committees. In addition it allowed funding to be provided to Australian States and Territories, and non government organisations, for the purpose of organ and tissue donation activity.
- Individual State and Territory legislation governing organ and tissue donation and transplantation.

Prior to 2008, Australian states and territories were responsible for organ and tissue donation in their respective jurisdictions. Whilst some national guidelines did exist, there was a lack of cohesive effort in the sector.

On 2 July 2008, the Australian Government committed $151 million over four years to establish a nationally coordinated approach to organ and tissue donation for transplantation. This was announced as a new National Reform Agenda, ‘A World's Best Practice Approach to Organ and Tissue Donation for Transplantation’.

The main objectives of the National Reform Agenda are to improve access to life-saving and life-transforming transplants for all Australians through:

- Increasing the capability and capacity within the health system to maximise donation rates; and
- Raising community awareness and stakeholder engagement across Australia to promote organ and tissue donation.
In Australia, the key organisations and associations that govern, regulate or have a role in organ and tissue donation include:

The Australian Organ and Tissue Authority (AOTA or the Authority), whose role it is to ensure a nationally coordinated approach to organ and tissue donation for transplantation in partnership with states, territories, clinicians, consumers and the community. The Authority is responsible for managing the implementation of the National Reform Agenda and for administering funds to state and territory government departments, hospitals and non-government organisations for organ and tissue donation services and activities.

The DonateLife Network comprises the Australian Organ and Tissue Authority, hospital-based medical and nurse specialists in organ and tissue donation, and state and territory Organ and Tissue Donation Agencies (OTDAs), led by State Medical Directors. Organ and tissue donation agencies are responsible for determining donor medical suitability and coordinating the retrieval of organs for transplantation. Agencies also provide donor family support services and educate health professionals and the general public about organ and tissue donation.

The National Health and Medical Research Council (NHMRC) has developed a number of discussion papers providing information and advice about ethical practice in organ and tissue donation and transplantation. The NHMRC also developed the ‘National Protocol for Donation After Cardiac Death’.

The Australian and New Zealand Intensive Care Society (ANZICS) is the peak professional and advocacy body for medical practitioners specialising in the treatment and management of critically ill patients. The ANZICS Committee on Death and Organ Donation developed the ‘ANZICS Statement on Death and Organ Donation’ which are guidelines for the determination of brain death and irreversible cessation of the circulation. The ANZICS statement also includes information pertaining to the clinical management of potential donors and recommendations regarding communication with families.

The Transplantation Society of Australia and New Zealand (TSANZ) is comprised of scientists, doctors, transplant coordinators and research students with an interest in transplantation. The TSANZ has a number of advisory committees that act as the peak body for their special interest group in the areas of retrieval, allocation and standards of practice. The TSANZ develops eligibility criteria for patients to be listed for organ transplantation and protocols for the allocation of organs to patients once listed. These are listed in the Consensus Statement ‘Organ Transplantation from Deceased Donors - Eligibility Criteria Guidelines and Allocation Protocols’.

The Australasian Transplant Coordinators Association (ATCA) is the professional body that represents donation and transplant coordinators and others working in organ and tissue donation and transplantation in Australia and New Zealand. ATCA has developed the ‘ATCA National Guidelines for Organ Donation’ as well as other procedural documents. ATCA also provides professional education opportunities for its members.

The Therapeutic Goods Administration (TGA) regulates all therapeutic goods available for supply in Australia, including tissue and cellular products (not solid organs). In order to comply with the Therapeutic Goods Act (1989), blood and tissue banks must meet the

The Australasian Tissue and Biotherapeutics Forum (ATBF) is the peak industry body for the tissue sector. It grants membership access to its Ratified Documents, which provide guidance, and define minimum standards for member organisations. ATBF also provides professional education opportunities for its members.

The Eye Bank Association of Australia and New Zealand (EBAANZ) is the peak body for eye donation and transplantation in Australia and New Zealand. It develops standards to ensure consistently acceptable levels of quality, proficiency and ethics in dealing with eye tissue for transplantation.

The Australia and New Zealand Organ Donation (ANZOD) Registry records and reports on data for deceased organ donors. The Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) collects statistics which relate to the outcomes of treatment of those with end stage renal failure.

The Transplant Nurses’ Association (TNA) is a professional body for nurses and health professionals engaged or interested in the care and/or treatment of patients involved in the transplantation process. It provides standards of care for its members as well as professional education opportunities.

The Australian Organ Donor Register (AODR) is the only national register for people to record their decision about becoming an organ and/or tissue donor. It is administered by Medicare, part of the Australian Government’s Department of Human Services.
Organ Donation and Culturally Diverse Groups in Australia

The development of organ and tissue donation resources for culturally and linguistically diverse (CALD) groups, has only recently become a national focus in Australia. Apart from some individual states and territories creating CALD resources prior to the creation of the Australian Organ and Tissue Authority (AOTA), there has not been a national effort in this area.

Research commissioned by AOTA has found that people from CALD backgrounds are less likely to have discussed organ donation with their family or made a decision about becoming an organ and tissue donor.

In 2011, AOTA awarded Community Awareness Grants to various organisations to allow them to conduct a range of education activities, as well as produce resources, specific to organ and tissue donation in CALD communities. As a result of these grants, a range of culturally-appropriate resources were developed. Many of these were produced in the language most often used in the community for which they were developed. Resources have been created for nineteen culturally and linguistically diverse groups. These are available on the AOTA website.

The Northern Territory (NT) benefited from the AOTA grants, with an arts organisation, Artback NT, receiving a grant to develop a play designed to broaden the understanding of Indigenous people about organ and tissue donation. This play toured the NT in 2012 and was very well received by Indigenous audiences.

One of the Australian Organ and Tissue Authority's strategic priorities for 2012/13 is to implement a nationally coordinated culturally and linguistically diverse audiences communication and engagement plan, to address barriers to decision making and discussion about organ and tissue donation. This will include the distribution and use of culturally appropriate resources.
Organ and Tissue Donation and Indigenous Australians in the Northern Territory

The Northern Territory (NT) occupies over 1.35 million square kilometres with a population of approximately 232,400 people (Australian Bureau of Statistics, December 2011), making it the least populous of all Australia’s states and territories. Whilst the majority of the NT population resides in the major centres of Darwin and Alice Springs, there are many regional centres and communities scattered throughout the NT. More than 100 nationalities are represented in the Northern Territory’s population.

While Indigenous (or Aboriginal) Australians comprise approximately 2.5% of the total Australian population, Indigenous Territorians make up approximately one third (33%) of the overall population of the Northern Territory (Australian Bureau of Statistics, 2006). Over 80% of Indigenous Territorians live in remote or very remote localities.

Chronic diseases including cardiovascular disease, diabetes and end stage renal disease are far more prevalent in Indigenous Australians compared to the general population. Indigenous Australians are generally over-represented in the organ-failure patient group, with kidney failure a particular concern. The Northern Territory has the highest national incidence among Indigenous people of treated end-stage kidney disease in Australia.

Transplant rates for Indigenous Australians in the NT are lower than the national average. Contributing factors include the low number of Indigenous organ donors, distance from interstate transplanting hospitals, and the ability to complete the 'work-up' for transplant.

Since 2007, there have only been 14 Indigenous organ donors in Australia, compared to 1336 non-Indigenous donors (Australia and New Zealand Organ Donor Registry data to end 2011) - representing only 1% of the total donors in Australia. This is proportionally less than the Indigenous Australian population composition, and considering the increased transplantation need among Indigenous Australians, it is critically important that this number increases markedly.

Matching donor organs to a recipient is done by comparing tissue types, also known as Human Leukocyte Antigen (HLA) types. When people share the same HLA, their tissues are immunologically compatible and this lessens the possibility of organ rejection. HLA are different in Indigenous Australians compared to non-Indigenous Australians. A HLA match is more likely if an Indigenous recipient receives an organ from a donor of their own ethnic group. Few Indigenous donors mean that Indigenous people on the transplant waiting list are less likely to be matched with a compatible organ donor.

The Northern Territory organ donation agency was established in November 2001 to coordinate organ donation in the NT, support donor families and provide the community and health professionals with appropriate education about organ and tissue donation. At the time the agency was established it was not routine practice to ask Indigenous families of patients in hospital about organ donation as it was thought that Indigenous people ‘did not believe’ in organ donation.

There is sparse research or literature on attitudes of Indigenous Australians towards organ donation. In 2003, the Northern Territory donation agency completed a small qualitative study into the thoughts of Aboriginal Health Workers (AHWs) at Royal Darwin Hospital on the topic of organ donation. The small group of AHWs involved in this study gave an insight
into the attitudes of Aboriginal people towards organ donation. They felt that although cultural and spiritual views may contribute to a refusal to donate organs, it was primarily their view that a lack of information on the subject meant they were unable to make an informed decision. Thus it appeared clear there was a need to develop a culturally appropriate organ and tissue donation education program. When implemented, it would provide Indigenous families with the information they required to make an informed decision about organ and tissue donation.

Concerns about organ donation raised by the AHWs are not unique to Indigenous Australians. Often such concerns can be allayed with the provision of specific information during family meetings or using appropriate community education materials. The lack of culturally appropriate educational material for Indigenous Australians, as well as others from culturally and linguistically diverse backgrounds, has made it difficult to provide meaningful information to these groups.

In 2003, it became the policy of Royal Darwin and Alice Springs hospitals to discuss organ donation with all Indigenous families of patients that had progressed to brain death. These discussions were always led by an intensive care specialist with knowledge and expertise in both communicating with grieving families and explaining the concepts of brain death and organ donation. Up until 2008, conversations regarding organ donation were held with many Indigenous families, the majority of whom were from remote communities. Unfortunately the majority of family members (with relatives admitted to the Intensive Care Unit) had not previously been given the opportunity to learn about the meaning of brain death or the idea of organ donation. Understandably, no Indigenous family members consented to organ donation during this period.

Such discussions and the lack of Indigenous donors, highlighted the need to develop resources to aid in hospital discussions with Indigenous families. In addition, it was felt that broader Indigenous community education strategies would also need to be developed so people could be educated about these concepts in their community, and in turn make an informed decision for themselves and their families if required to do so.

In 2008, the NT organ donation agency employed a talented local graphic designer - Therese Ritchie - to assist in producing a series of educational resources for an Indigenous audience regarding brain injury, organ donation and transplantation. Therese and I worked in close consultation with three kidney transplant recipients - Jeannie Herbert, Didamain Ulbo and David Croker - over a two-year period to develop the resources. A local production company - Cutting Edge - was also engaged to produce a DVD describing the issues of organ donation and transplantation from the perspective of the three kidney transplant recipients.
The resources produced are listed below.

- A book titled 'The Brain Story' and a book titled 'The Organ Donation Story'. Both are full colour books which use narrative, photographs and illustrations in a story book format.

![Sample pages from the Brain Story Book](image1)
![Sample pages from the Organ Donation Story Book](image2)

- An eighteen minute documentary DVD 'If You Want To Give Life', which describes the issues of organ donation and transplantation through the stories of three Indigenous kidney transplant recipients.

- A series of seven 'Love Your Body Organs' posters (male and female versions) showing the major body organs (heart, lungs, liver, kidneys and pancreas), how they work and how to keep them healthy. Two further posters provide a visual description of how smoking and alcohol can affect the major body organs. These were developed as a result of feedback from the Indigenous reference group stating there was not enough understanding in communities about how the body worked and the role of the body's vital organs. They suggested that any educational material about organ donation be presented with an explanatory and preventative component so that Indigenous audiences could come away with positive information about the body, important body organs and how to keep them strong.
The resources were initially trialled in the hospital setting prior to a pilot project being undertaken in a community setting.

Piloting of the resources was conducted in two Northern Territory communities, Wurrumiyanga (formerly Nguiu) on the Tiwi Islands located 80km N/NW of Darwin, and Ltyentye Apurte (otherwise known as Santa Teresa) located 80km E/SSE of Alice Springs. The pilot project began in June 2011 and continued through until August 2012.

As the pilot progressed, there appeared to be an increase in the level of community awareness about body organs and organ donation, and there was certainly an increase in community interest, as evidenced by repeat invitations to return to the communities. Coinciding with the pilot project, the Northern Territory experienced a significant rise in its organ donation rates, and this included two Indigenous families generously agreeing to donate their loved one's organs for transplantation.

*Copies of the Indigenous Education Resources developed in the Northern Territory were provided to all organisations I visited as part of my Fellowship.*
Main Body

Organ and Tissue Donation in the United States

Notable facts and information:

- Over 116,000 people are on the United States organ transplant waiting list.
- Over half of those on the waiting list are ethnic minorities.
- In 2011, there were 8,127 deceased organ donors and 6,017 living organ donors resulting in 28,535 organ transplants.
- An average of 18 people die each day in the US from the lack of available organs for transplant.
- The United States allows directed donation, whereby families request organs be allocated to a specific recipient (friends or family) on the transplant waiting list.
- A National Donor Recognition Ceremony is held biennially in Washington DC. This includes presentations to donor family members as well as a series of educational and support workshops. Organ procurement organisations also hold donor ceremonies in their own state.
- Studies show 90% of Americans say they support organ and tissue donation.
- National Donate Life Month is held annually in the United States during the month of April.

US organ and tissue donation authorities and organisations

Organ and tissue donation is a highly regulated sector in the United States. There are a multitude of authorities in the organ and tissue donation arena responsible for oversight, regulation, funding, auditing, organ procurement, family support, hospital and professional development and community education.

I would like to thank Elling Eidbo, Executive Director, Association of Organ Procurement Organisations and Jennifer M Porter, Attorney at Law, both of whom I met while in Washington, and who did a remarkable job of explaining the extensive regulation and legislation applicable to organ and tissue donation in the United States.

The key pieces of legislation governing organ and tissue donation are:

- The National Organ Transplant Act (enacted in 1984). This Act prohibits the sale of human organs and mandated the establishment of the Organ Procurement and Transplantation Network (OPTN), and the Scientific Registry of Transplant Recipients (SRTR). It also provided grant funds for qualified Organ Procurement Organisations (OPOs) and enabled the establishment of a Task Force on Organ Transplantation.
- The Uniform Anatomical Gift Act (enacted 1968, revised 2006). This Act provides uniformity in law governing organ and tissue donation. It mandates that hospitals ascertain and uphold the donation wishes of individuals and families, and gives
priority to the decedent's wishes over the decedent's family members (in regards to possible objections to organ donation by family members). This has been adopted in various forms by US states.

- Individual US State and local laws governing organ donation.

In the United States, the key organisations and associations that govern, regulate or have a role in organ and tissue donation are listed below.

The US Department of Health and Human Services (HHS) has overall oversight of organ and tissue donation in the United States. The Division of Transplantation (DoT) within the HHS agency, the Health Resources and Services Administration (HRSA) is responsible for this oversight as well as funding support for donation research and activities.

The Centre for Disease Control (CDC) publishes guidelines to prevent the risk of disease transmission through transplantation. Most recently it has published (in draft form) the 'Public Health Service Guideline for Reducing Transmission of HIV, Hepatitis B Virus, and Hepatitis C Virus through Solid Organ Transplantation' and this is currently being revised.

The Centres for Medicare & Medicaid Services (CMS) regulate all hospitals that receive any type of federal reimbursement. All hospitals in the United States which are involved in organ donation and transplantation must ensure they comply with CMS regulations, which hold these hospitals accountable for their donation programs. In terms of organ and tissue donation, these regulations are described in rules called 'CMS Conditions of Participation for Hospitals'.

Key points of the 'CMS Conditions of Participation for Hospitals' include:

- Hospitals must report all deaths to the OPO in a timely manner within one hour of a patient exhibiting signs of imminent neurological death or within one hour of cardiac death to enable eye and tissue donation.

- Only OPOs are allowed to determine medical suitability for donation (this cannot be determined by hospital staff).

- Only an OPO staff member or a trained, designated requester may approach the family of a potential donor for consent for organ, tissue or eye donation.

The United Network for Organ Sharing (UNOS) is a private, non-profit organisation that manages the United States' organ transplant system under contract to the Human Resources and Services Administration (HRSA) of the US Department of Health and Human Services. UNOS manages the national transplant waiting list, undertakes policy development, maintains UNet (a database that collects and analyses data regarding patient waiting lists, organ matching and transplantation), provides professional education and aims to increase public awareness. The majority of UNOS funding is derived from membership fees, charitable contributions and project grants, with less than 10% of its funding being provided by the Federal Government.

The role of the Organ Procurement and Transplantation Network (OPTN) is to increase the availability of donor organs for patients with end-stage organ failure. It is administered by UNOS under the US Department of Health and Human Services.
The Scientific Registry of Transplant Recipients (SRTR) supports the development of evidence-based allocation policies, encourages research in transplantation and provides a national database of statistics related to solid organ transplantation. It is administered by the Chronic Disease Research Group of the Minneapolis Medical Research Foundation.

There are 58 federally-designated and regulated OPOs in the United States. These organisations are assigned geographical service areas by the CMS and are obligated to serve all hospitals in their assigned area. OPOs determine donor medical suitability and coordinate the procurement of organs for transplantation. OPOs also provide donor family support services and educate health professionals and the general public about organ donation. OPOs are responsible for all expenses related to the donation process. They obtain funding from fees charged to the transplant hospitals receiving the organs for their transplant patients (which is regulated through Medicare), as well as through fundraising.

Each OPO is generally structured to include a hospital development team, a clinical services team, a donor family services team and community education staff. A description of these teams is provided below.

**Hospital Development:** The hospital development staff act as a liaison between the OPO and hospitals within the OPOs service area. These staff work with hospital employees, including administrators and healthcare staff, to develop organ donation policies tailored to the hospital's requirements. These policies underpin organ donation cases within each particular hospital. Hospital development staff also provide tailored education and training to hospital personnel. Depending on the OPO and circumstances surrounding the potential donation, hospital development staff may be sent to a hospital to provide support during a donor case.

**Clinical Services:** Clinical services staff manage the donor clinically, provide information to UNOS to allow organ allocation, and manage the organ retrieval process in theatre. Some clinical services staff support donor families (in conjunction with donor family services staff members) and some may recover tissue for transplantation.

**Donor Family Services:** The donor family services team provides support, information and resources to the donor family during a donation, as well as ongoing support for years after the donation. Donor family services teams coordinate remembrance services and other commemorative activities for their OPO. They also facilitate communication between donor families and recipients and in some cases, if requested by both parties, they assist families in their request to meet each other.

**Public Affairs and Community Education:** The focus of the public affairs and community education team is to increase awareness in the community about the benefits of organ donation and encourage individuals to register their donation intention on their driver’s licence. The focus of their efforts is generally based at community events, through media, with Departments of Motor Vehicles (DMVs), and at workplaces, schools and places of worship.

In addition, some OPOs have a team of quality assurance staff and incorporate tissue banking within their service.
*Donate Life America* is an alliance of national organisations and local coalitions dedicated to educating the public about organ, eye and tissue donation. It publishes brochures, program kits and other educational materials to assist in increasing donation rates. Whilst Donate Life America provides merchandise for distribution by its coalitions, it also sells merchandise to the public through its online store. This includes items such as T-shirts, bags, stickers, balloons, wristbands and many other items.

In January 2012, Donate Life America launched an initiative to register 20 million people on state donor registries in the calendar year. To help achieve this, they released a series of ‘*I am HOPE*’ videos and also planned four key national events, listed below, which many of the OPOs I visited were involved in:

- ‘*Donate Life Flash Mob*’ - on 24 March 2012, flash mobs were held across the country to generate media and raise awareness of donation.

- ‘*Donate Life Blue and Green Day*’ - with blue and green being the Donate Life brand colours, the public was encouraged to wear these colours on 20 April 2012.

- ‘*Donate Life Champions*’ - the public and organisations were encouraged to identify local athletes, coaches, teams and sports broadcasters and add them to the list of Donate Life Champions. Donate Life Champions were encouraged to ask their fans (through social media) to support organ and tissue donation.

- ‘*Donate Life Linking Hands for Life*’ - people were encouraged to get a large group together, dress in Donate Life T-shirts and link hands, with the aim of raising awareness about donation and obtaining media interest.

Whilst in the United States I noted the popularity of displaying flags outside businesses and even private houses. Donate Life America has capitalised on this by providing flags to hospitals and OPOs to fly as part of Donate Life month in April. They also sell miniature flags through their online store.

The *US Food and Drug Administration* (FDA) regulates human cell, tissue, and cellular and tissue-based products through its Centre for Biologics Evaluation and Research. The FDA requires that tissue banks and tissue suppliers are registered with them and periodically inspects them to ensure compliance with Federal regulations.

The *American Association of Tissue Banks* (AATB) is the national tissue banking organisation in the United States. It publishes standards for tissue banking and accredits tissue banks (more than 100 tissue banks are members of the AATB).

The *Eye Bank Association of America* (EBAA) is the national accreditation association for eye banks in the United States. It publicises standards and procedures for eye banks and conducts three-yearly inspections of banks to ensure compliance.

The *Association of Organ Procurement Organisations* (AOPO) is the professional organisation that represents the fifty-eight federally-designated OPOs in the United States. AOPO has developed organisational and ethical standards for OPOs. AOPO has councils, committees, task forces and work groups whose work is set and guided by the AOPO Executive Committee. AOPO has a voluntary accreditation program that assists OPOs to comply with federal regulations and AOPO standards. AOPO offers education and
professional development opportunities to its members. It also works closely with Congress in Washington in regard to legislative issues related to organ and tissue donation.

The **North American Transplant Coordinators Organisation** (NATCO) is the professional body that represents donation and transplant professionals in the United States. It provides professional development and networking opportunities for its members and publishes the ‘Progress in Transplantation’ journal. NATCO holds positions on UNOS/OPTN committees and provides input into legislative debates in Washington DC.

The **American Board for Transplant Certification** (ABTC) formulates policies, establishes educational standards and provides certification opportunities to members. ABTC provides four types of certification, depending on areas of specialty.

Protocols and resolutions of note with respect to US organ and tissue donation activities are outlined below.

In 2000, the US Department of Health and Human Services issued the ‘Final Rule’ which dictates protocol for cadaveric organ donation. The ‘Final Rule’ replaced a variety of local and regional protocols with a unified policy and increased the Department of Health and Human Services’ control of organ donation. Prior to the implementation of the ‘Final Rule’ the US had an inequitable organ allocation system which favoured geographical areas with large donor banks. The ‘Final Rule’ altered the way organs were allocated to ensure allocation of organs to the sickest patients first without regard to geography (except when the transportation of organs would threaten their suitability for transplantation). The ‘Final Rule’ as it stands today allows for local recipients to be considered first but directs organ procurement organisations to offer organs nationally if a local match cannot be made, taking urgency of need into account.

In 2010, the **National Association Of Attorneys General** (NAAG) passed a resolution that:

- affirms that state law recognises the individual’s right to make an anatomical gift that cannot be amended or revoked by any other person, except with the donor’s consent; and

- affirms that it is the obligation of all participants in the donation process - hospitals, doctors, procurement organisations, and family members - to comply with the law and to honour, and implement the decision of the donor.

In each of the OPOs I visited, I was advised that they follow through with ‘first person consent’ in almost every donation case. They inform families of their loved one’s wishes in regards to donation and advise how they are going to ensure these wishes are honoured.

Other points of interest I noted whilst in the United States are detailed below.

Each state in the US has an Organ and Tissue Donor Registry. Either the **Department of Motor Vehicles** (DMV) provides the local OPO with donor information collected from driver’s licences, or the OPO collects the information itself. The registries are heavily promoted by OPOs as part of their public education programs. **Donate Life America** publishes a ‘**National Donor Designation Report Card**’ annually which lists the number of people enrolled in state donor registries.
It was apparent that volunteer groups were very highly valued by all OPOs. Donor family members, transplant recipients, and community members touched by organ and tissue donation provide voluntary services to assist OPOs in their education efforts. Volunteer groups are coordinated by OPOs and provided with training to ensure accuracy in the provision of information. Many of the OPOs I visited had employees who had been directly touched by organ and tissue donation, either as a donor family member or as a recipient.

The performance measure of 'donors per million population' (dpmp) is now rarely used in the United States. Conversations I had with OPO staff highlighted problems with using this measure as it:

- represents a potential supply of donors that does not actually exist i.e. it does not measure the number of actual donors in comparison to those who are actually eligible to be donors;
- assumes that countries or regions are identical except for their donation programs and does not account for variations in demographics, or social and mortality characteristics (such as cause of death) which affect organ donation rates; and
- populations with above-average clinical donation potential or a greater propensity to donate will always have higher dpmp rates.

Thus for the reasons stated above, OPOs in the United States no longer use dpmp as a measure of effectiveness. Comparisons in donor rates in the US now take into account specific characteristics in each donation service area, with OPOs measuring:

- the number of eligible deaths (potential donors);
- the number of organs transplanted per donor (US national aim is 3.75); and
- the eligible death conversion rate (US national aim is 75%).
Organ Donation and Culturally Diverse Groups in the United States

- More than half of the United States national transplant waiting list is made up of multicultural populations. This equates to over 64,000 people.

- The largest minority population group in the United States in need of a transplant are African-Americans.

- The following table compares ethnicity in regards to population representation and the percentage of people on the US transplant waiting list:

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>% US Population</th>
<th>% on Transplant Waiting List</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caucasian</td>
<td>64%</td>
<td>45%</td>
</tr>
<tr>
<td>African-American</td>
<td>13%</td>
<td>29%</td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>16%</td>
<td>18%</td>
</tr>
<tr>
<td>Asian</td>
<td>5%</td>
<td>6.5%</td>
</tr>
<tr>
<td>Native Hawaiian/Pacific Islander</td>
<td>0.4%</td>
<td>0.5%</td>
</tr>
<tr>
<td>Other</td>
<td>-</td>
<td>1.1%</td>
</tr>
</tbody>
</table>

- People of different ethnic backgrounds generally donate in proportion to their representation within the population.

- Unfortunately the need for transplantation is disproportionally higher in some ethnic groups. This is due to a high incidence of chronic disease among these population groups leading to end-stage organ failure. This is particularly the case for African-Americans, who are three times more likely to develop end-stage renal disease than Caucasians.

- In 2003, the United Network for Organ Sharing (UNOS) changed the way it allocated kidneys in an effort to increase transplants for African-Americans. Aspects of HLA matching were removed from the allocation criteria as it was viewed as a less important criterion given the advances in immunosuppression. A study published by the *American Journal of Kidney Diseases* (November 2011), showed that while this did significantly increase the number of African-American transplants, an increased transplantation need still existed in this population group.¹

The US Department of Health and Human Services (HHS) publishes information on its website regarding minority groups and donation. Stories regarding donor families and recipients from different minority groups are published in sections specific to that minority group. The website also provides links to the Office of Minority Health (OMH) and information regarding the health profiles of different minority groups.

The HHS Department publishes a 'Multicultural Outreach Toolkit' for minority audiences including African-Americans, Hispanics/Latinos, Asians, and Native Hawaiians and Other Pacific Islanders. The toolkits are available in downloadable form or can be ordered from the website. These contain stories of donors and recipients, statistics relevant to minority groups, information regarding religious views on donation, myth-busting information (specific to cultural groups), press release templates and live read radio scripts (in English and Spanish). Community role models also feature in awareness campaigns.
The Division of Transplantation (DoT) within the Human Resources and Services Administration (HRSA), funds grant programs for research projects relating to organ and tissue donation and transplantation. A large proportion of HRSA grants have funded research projects with a focus on improving organ donation awareness and intent to donate in minority groups.

National Minority Awareness Week commences annually on 1 August in the United States. Previously an awareness day, the Week honours minority group members who have become organ and tissue donors, and raises awareness of organ and tissue donation through various events across the country. The Week also has a preventative component in that it encourages groups to take care of their health, by providing information on preventable diseases and health promotion tips regarding these. National Minority Awareness Week was founded by Dr Clive Callender, who also founded the ‘Minority Organ Tissue Transplant Education Program’ (MOTTEP).

In 1978, an awareness of the shortage of minority donors led to development of an African-American focus group, convened by Dr Callender, with the aim of understanding why minorities were reluctant to become organ donors. The focus group identified five key obstacles for minority groups:

- lack of awareness;
- religious beliefs and misperceptions;
- distrust of the medical community;
- fear of premature death after signing a donor card; and
- fear of racism

They also learned that face-to-face discussions with culturally sensitive and ethnically similar messengers helped overcome these obstacles.

In 1991, MOTTEP was created to educate all ethnic minority groups about organ and tissue donation. This national initiative was funded primarily by the HHS National Institutes of Health (NIH), as well as other sources. The program encourages communities to develop grassroots education programs and increase the number of minorities who donate organs and tissues. It utilises culturally sensitive and ethnically similar transplant recipients, donor family members, living donors and people on waiting lists, who partner with donation professionals and organisations, to spread its messages through presentations, media and other strategies. In recent years, MOTTEP was expanded to include a preventative component, to educate communities about the diseases and behaviours that may lead to a need for transplantation.

MOTTEP has been rolled out in ten sites across the United States, including Hawaii, New York, and Washington and reaches an average of 700,000 people annually. Evaluation of the program indicates that the strategies used have contributed to an increase in knowledge and awareness and sustained behavioural changes including signing donor cards and discussing donation with family members. A study published in the Journal of the American College of Surgeons (May 2010) showed that minority organ donations have more than
doubled since the introduction of grassroots awareness and education programs. In 2010, the percentage of minority donors was expected to reach 35 percent, up from only 15 percent in 1990.

The Association for Multicultural Affairs in Transplantation (AMAT) aims to increase the number of organ and tissue donors in multicultural communities and increase the number of transplants for minority groups. AMAT holds an annual meeting where multicultural issues in donation and transplantation are discussed. Organisations or individuals can become members of AMAT and the majority of OPOs I visited were members and served on AMAT committees. The AMAT Multicultural Committee is responsible for helping to recruit and retain multicultural staff in OPOs as well as providing cultural information to assist AMAT members. This committee has subcommittees including the African-American Work Group, the Asian/Pacific Islander Work Group, and the Hispanic/Latino Work Group.

As one of their OPTN compliance measures, OPOs are expected to develop and implement programs addressing multicultural issues in organ and tissue donation. While visiting OPOs during the period of my Fellowship, the culturally diverse mix of employees within each organisation was very evident. In particular there were a large number of multicultural staff working in the areas of donor family services and community outreach.
Legacy of Life - Honolulu - Hawaii

Background

Hawaii has a population of 1.37 million people spread across four main islands. The majority of the Hawaiian population identifies as Asian (38.5%), with Caucasian (26%), Multi Race (23%) and Native Hawaiian or Pacific Islander (10%) being the other most populous ethnic groups. Hawaii is a unique population with respect to other US States in terms of its higher Asian and ethnic population and lower Caucasian population.

Legacy of Life is the only OPO in Hawaii. It is located in Honolulu on the island of Oahu (Hawaii's most populous island). Over the past five years, Legacy of Life has averaged 45 deceased donors per year. In 2011 Legacy of Life achieved an average of 2.28 organs transplanted per donor (the 2011 US average rate was 3.07).

In 2011, 52% of people in Hawaii (over the age of 18) were registered donors. Hawaiian residents can register to be an organ and tissue donor online or when applying for a driver's licence through a branch of the Department of Motor Vehicles. Each time a person renews their licence in Hawaii, they must re-register their donation status or it is erased from the system.

Fellowship Visit

Upon my arrival at the Legacy of Life offices in Hawaii, I was warmly welcomed with a fresh flower lei and given a tour of the organisation.

In the time spent at Legacy of Life, I met staff members from Donor Family Services, Hospital Development, Clinical Services, Marketing and Community Outreach and Tissue Procurement.

I had the opportunity to participate in group and individual meetings with the Donor Family Services Department. Family Services Coordinators are trained in grief support and receive cross-cultural training. Staff members from a variety of cultural backgrounds work as part of the Donor Family Services team.

Requesting organ donation from families of different ethnic groups is the norm in Hawaii with its very multicultural population. Consent approaches focus on the benefits of donation, the number of people on the waiting list (from the donor’s ethnic group), the respect shown during the retrieval, and the fact that families can view their loved one following the recovery procedure. The team offers support to donor families within hospitals in partnership with chaplains, social workers and interpreters and using written translations where necessary. At the time of donation, family members are provided with information booklets regarding brain death and organ donation. These are available in a variety of languages.

A relatively new form of technology has been used by the team when speaking to families from non-English speaking backgrounds. MARTI (which stands for My Accessible Real Time Interpreter) is a touch screen computer monitor that is connected to the internet and can be moved on a cart to a patient’s room. The MARTI network can then link OPO staff and donor families to an interpreter trained in translation and medical terminology. MARTI has access to interpreters that speak one or more of 150 languages, including sign
language. In the week I visited, the Family Services team had used this technology when speaking to a Vietnamese family.

Whilst each donation case is different, the following statements were provided to me by team members from the Donor Family Services department:

- Team members may be selected to attend family meetings, based on their cultural background but also based on their experiences with families;
- Families from a more urban setting are more likely to agree to donation than families from rural or remote areas;
- Traditional Hawaiian families often agree to donation as sharing and being community-minded is part of their culture;
- Micronesian families generally don’t agree with organ donation because of beliefs that alteration or intrusion of the body could harm the soul;
- First generation Filipino families were identified as being less likely to consent to donation; and
- Families of tourists are commonly asked to consider donation.

I was shown the various mementos or 'transition items' provided to donor families by Legacy of Life. These include:

- finger, foot or handprint impressions (which can later be made into memento jewellery called Thumbies);
- a heartbeat in a bottle (an electrocardiogram strip placed inside a glass bottle);
- a keepsake clay plate for handprint impressions;
- an angel bag (for locks of hair);
- a memory box (for important keepsakes);
- a memory album (for photos); and
- a prayer shawl

Legacy of Life mementos and transition items
The Donor Family Services team also offers support as part of their aftercare program. On average staff have fourteen contact opportunities with donor families in the first year post-donation. These include sending anniversary cards, birthday cards and support literature, Mothers Day and Fathers Day events, the annual Donor Recognition Ceremony (at which monarch butterflies are released), Hope for the Holidays (an annual afternoon of healing grief activities held each Fall prior to Thanksgiving, Christmas and New Year), and other events.

The following is a summary of what is offered as part of the aftercare program:

- A few weeks after a donation, an outcome letter is sent to the family providing recipient information such as age, gender, home state, time the recipient was on the transplant waiting list and some social information. Families are also provided with a folder containing bereavement and resource literature (grief booklets, support group information & literature on writing to recipients). This is customised to their loved one's age, circumstances of death and relationship of the donor to the family member.

- Families receive a framed Donor Memorial Certificate.

- Families are contacted again at three-months post-donation.

- At six-months post-donation, families receive a letter offering counselling support. Twice a year, one of the Donor Family Services staff members coordinates a six-week program 'Growing through Grief'. Families are also invited to join the Hawaii Donor Family Council and attend its monthly bereavement support group.

- Two sympathy cards are mailed to donor families (one to commemorate the donor's birthday and the other on the anniversary of the donor's death).

- Donor families receive seasonally-focused quarterly newsletters entitled 'Butterflywings', which contain information on grief and self-care, as well as recipes.

- Families are invited to contribute a fabric square commemorating their loved one which then forms part of a perpetual donor family quilt. Several quilt panels have been produced and these are hung within the OPO, the National Kidney Foundation of Hawaii and the Hawaii Lions Eye Bank. They are also taken to various community events in order to share donor family stories, increase public awareness and encourage community members to consider donation. A quilt book 'Na Makana Pau 'Ole' (Gifts without End) has also been produced. This features images of panels produced for the donor quilt and assists donor families to share their stories.

When I visited Legacy of Life, the Donor Family Services team were in the process of formalising the 'United With Hope' program which aims to unite donor family members with their loved one's transplant recipients. The OPOs past experience with this has demonstrated positive benefits for both donor families and recipients. This is a voluntary program and participants must have corresponded for a set period of time before being carefully screened and counselled prior to a potential meeting. To initiate the process, families are required to complete a questionnaire and a disclosure/release form. There is the opportunity to withdraw at any time. Information on the benefits and risks of meeting is
provided to donor families and recipients. Donor Family Services staff help locate a neutral site and facilitate the first meeting. Interpreters are provided when required. Depending on the family and circumstances, members of the media may be invited.

I was provided the opportunity to present to the Donor Family Services team in regards to organ donation in Australia and the Indigenous Education resources developed in the Northern Territory. This provoked thoughtful discussion and highlighted many similarities between cultures.

The Marketing and Community Outreach team's focus was on promoting the message 'Leave a Legacy of Life'. After what they viewed as too many years of focusing on addressing the public's potential misgivings about donation - and providing what they considered to be 'too much information' - they decided to switch their focus to a more 'positive' marketing approach. They produced a six-minute testimonial DVD, 'Life is Worth Giving', which features donor families and recipients and focuses on the positives of donation, as well a series of sixty-second radio commercials telling the stories of donor families and recipients. As part of this campaign, a basic marketing kit was developed. This contains a donor registry sign-on form, as well as 'Save a Life' brochures (with images of people from different nationalities). Key target businesses for the campaign include Departments of Motor Vehicles, workplaces, banks, places of worship, schools and universities. A large volunteer group assists in community outreach activities and also make green donation awareness ribbons for Legacy of Life.

As part of Legacy of Life's community outreach activities, middle and intermediate-aged school children across Hawai'i were recently invited to participate in a creative art competition to raise awareness of organ and tissue donation, and to introduce youth to the issue prior to them signing up for their first driver's licence. Twelve designs (judged by Legacy of Life staff to be the best) were chosen to form pages of a calendar. Members of the public can purchase a calendar for $15.00.

I spoke with some of the Legacy of Life Community Outreach team about their participation in the Minority Organ and Tissue Transplant Education Program (MOTTEP). Legacy of Life worked with MOTTEP of Honolulu on a program to increase organ donation awareness within the Filipino community.
The goal of the MOTTEP 'Bayanihan' (Working Together to Help) program was to increase cadaveric organ, tissue and eye donation by Filipinos in Hawaii through developing and implementing a state-wide outreach education program. The program was specifically tailored to the Filipino culture. The program involved:

- a review of records to determine Filipino-specific organ donation rates;
- conducting surveys of Filipino community members, those on the waiting list and community leaders and volunteers who had been involved in any aspect of minority donation;
- the development of a leadership council comprising members from business, labour, religious groups, government, media and youth groups and holding quarterly council meetings;
- developing organisational partnerships (each island council had a standing committee assigned to donation);
- developing ties with the Filipino Nursing Organisation of Hawaii;
- the establishment of a media campaign committee, grassroots education campaign committee, volunteer recruitment committee, religious community outreach committee and a family approach committee;
- holding annual retreats to define implementation strategies to achieve the goals and objectives of the program;
- the development of education materials;
- volunteer training with an emphasis on consistent messaging, family discussion and signed donor cards; and
- allowing trained volunteers to assist with family consent approaches.

This program was highly successful with the Filipino donor consent rate increasing from 3% when the program commenced to 27% within four years. In Hawaii, Filipino donation consent rates have increased steadily to a high of 71% in 2006. Whilst other factors may have influenced this, it is likely the MOTTEP Program has been an enormous contributing factor in this increase.

The Clinical Services Director provided me with an overview of the responsibilities of the Clinical Services team. When a notification is received from a hospital about a pending death, a member of the Donor Family Services team goes to the hospital to speak to the family, while a Clinical Services Procurement Transplant Coordinator triages referral information and determines the need for an onsite visit. Should the family consent to organ donation, a Transplant Coordinator implements donor management protocols and oversees organ allocation, while the Donor Family Services team provides support and information to the donor family.
All potential donors and the status of each case is tracked on the iTransplant system. iTransplant is a web-based software system that allows procurement organisations and transplant teams to enter information to improve, increase and expedite organ, tissue and eye donation and transplantation. A vast array of information can be entered into, or connected to, the iTransplant system including: results of medical tests, donor referral information, case note logs, allocation and offer details and other pertinent information.

There is only one abdominal transplant centre in Hawaii which can perform pancreas, liver and kidney transplants. Lungs are not retrieved for transplant due to extended ischaemic times. Hearts may be recovered but timing is critical to ensure a heart retrieved for transplant can make it to the US western mainland states in an appropriate timeframe.

There are clinical challenges to undertaking the donation process in Hawaii including the need to have blood tested on mainland USA, having to transport donated hearts to mainland states and having to travel to other Hawaiian islands to assess potential donors and retrieve organs.

During my time at Legacy of Life I was provided an overview of the Hospital Services Department role. Staff in this area collaborate with a portfolio of several of the fifteen Acute Care hospitals in Hawaii and ensure organ and tissue donation hospital agreements and policies are kept updated. They also ensure compliance with federal and state legislation and regulations.

I was provided an overview of the recently established tissue donation program and given a tour of the facilities and equipment relating to this. Consent for tissue retrieval is established by telephone. Tissue is currently retrieved from donors up to the age of 70 years, although it is hoped to extend this to 75 years.

On my final day with Legacy of Life, I had the opportunity to tour the Hawaii Lions Eye Bank which is co-located within the same building. The Eye Bank collects, processes and supplies eye tissue for corneal transplants for the people of Hawaii. Almost 200 corneal transplant operations are performed in Hawaii each year and there is currently no waiting list.

Lee Wood, son Mark and Ruth Peterson in Hawaii
OneLegacy - Los Angeles - California

Background

Los Angeles city has a population of about 3.8 million people and is the second most populous city in the United States. The majority of the population serviced by OneLegacy identifies as Hispanic/Latino (45%), with Caucasians (34%), Asians (12%) and African-Americans (7%) the other major ethnic groups.

OneLegacy is one of four OPOs in California. It services 215 hospitals, 11 transplant centres and a population of almost 19 million in Los Angeles and its 6 surrounding counties. Over the past five years, OneLegacy has averaged 389 deceased donors per year. In 2011, OneLegacy achieved an average of 3.01 organs transplanted per donor (the 2011 US average rate was 3.07). OneLegacy consent rates for Caucasian, Hispanic/Latino and Asian families all significantly increased in 2011.

In 2011, 31% of people in California (over the age of 18) were registered donors. Californian residents can register to be an organ and tissue donor online or when applying for a driver's licence through a branch of the Department of Motor Vehicles. When registering through the DMV, in addition to being placed on the Registry, a pink 'DONOR' dot symbol is pre-printed on the applicant's driver's licence.

Fellowship visit

OneLegacy has over 300 staff who undertake roles in departments including Donation Development, Organ and Tissue Procurement, Surgical Recovery, Donor Family Care, Donor Information, Referral and Allocation, Research and Education, Media and Communication, Quality Assurance, Finance, Human Resources and Information Technology.

Upon my arrival at OneLegacy, I was provided a tour of the Donor Referral Centre and the supply and sterilisation areas. OneLegacy utilises a customised electronic referral system, digitalDonor which tracks potential donors and the status of each donor case. I was able to meet with allocation staff to see how this system functioned. Observing the efficiency with which organs could be allocated using an electronic system certainly reinforced to me the benefits that would be gained through Australia's planned introduction of an electronic donor record and allocation system.

During my tour of the area I noted that organ packaging labels (for transport containers and organ bags) were provided in different colours on waterproof paper. I particularly liked this idea (as it reduces the possibility of labelling errors) and thought it would be a useful system to introduce in Australia (which currently utilises labels which are the same for all organs and tape for labelling and securing organ bags).
I spent a significant amount of time with OneLegacy’s Media and Communications team members learning about the work they do. Staff members from a wide variety of cultural backgrounds work as part of this team.

Donate Life Ambassadors, OneLegacy’s official volunteer program, offers donor family members, transplant recipients and others touched by donation or transplantation an opportunity to share their experiences and inspire their own communities to ‘donate life’. Done Vida Ambassadores (Spanish-speaking Donate Life Ambassadors) are the volunteer group for Hispanic/Latino people. All of OneLegacy’s Donate Life educational material is provided in both English and Spanish. The Done Vida California website mirrors the Donate Life California website, with all information translated into Spanish.

Ambassadors/Ambassadores attend training workshops to enable them to provide accurate information to their communities. The workshops focus on myth busting, expectations, boundaries and how best to share stories effectively. Ambassadors are also sent a newsletter entitled ‘The Key’ which highlights the activities of Donate Life Ambassadors.

Six key programs that engage Ambassadors in community service include:

- ‘Ambassadors to DMVs’ - educate and build relationships with DMV office staff to encourage them to support donor registry enrolment.

- ‘Ambassadors to Cities’ - engage civic leaders in their community to make organ and tissue donation a community responsibility. During March and April of each year, Ambassadors to Cities contact their civic leaders to be part of the annual Donate Life Run/Walk and encourage their communities to sign onto the Donate Life California Registry.

- ‘Ambassadors to the Media’ - reach out to local print media in their community to tell donor family or recipient stories.

- ‘Ambassadors to High Schools’ - encourage high schools to implement organ and tissue donation education in their health classes. This helps to provide students with information enabling them to make an informed donation decision when applying for their driver's licence.
• ‘Ambassadors to Hospitals’ - share their personal stories with hospital staff who impact donation opportunities or are involved in the donation process.

• ‘Ambassadors of eCampaigns’ - encourage friends and colleagues to register as organ and tissue donors via personalised pages on the Donate Life California Registry website.

OneLegacy is well renowned throughout the United States for its coordination of the Donate Life Float for the Tournament of Roses Parade, known as the Rose Parade, held on the 1st of January each year. This parade celebrates America's New Year and is held annually in Pasadena, California. The parade contains a huge number of flower-decorated floats and since 2004, a Donate Life float has been part of the celebrations. The float carries transplant recipients, living donors and family members of deceased donors. It also displays dozens of memorial ‘floragraph’ portraits of deceased organ and tissue donors which are integrated into the float design. It also contains hundreds of dedicated roses. The Australasian Transplant Coordinators Association (ATCA) has previously sponsored a memorial rose on behalf of Australian organ and tissue donors.

The Donate Life Hollywood program is also based in Los Angeles. This program aims to be a liaison between the fields of organ donation/transplantation and the entertainment industry. It can help writers and actors gain access to specialists so those in the industry may research storylines and accurately portray characters on television and in movies. Donate Life Hollywood presents awards for films/television series and to film-makers and celebrities who provide positive and factual information on organ and tissue donation.

In terms of multicultural outreach, OneLegacy and its volunteers target events/places of importance to different ethnic communities. When providing information to different ethnic groups, OneLegacy staff and volunteers focus on finding connections and educating people about the potential benefits of donation for their community. Educational and promotional material has been developed in multiple languages for ethnic communities.

Examples of the multicultural brochures used by OneLegacy
Examples of events OneLegacy and its volunteers have been part of include:

- ‘Mexican Independence Day Parade’ - Done Vida staff, volunteers and donor families marched in this parade in Los Angeles holding pictures of donors. Done Vida also hired a bus which they decorated with organ donation promotional material. This event was televised locally.

- ‘Kingdom Day Parade’ (in memory of Martin Luther King) - Donate Life staff, volunteers and donor families entered a float in the Kingdom Day parade representing the ‘Faces of Donation and Transplantation’. This event was televised locally.

- ‘National Donor Sabbath’ - observed two weekends prior to Thanksgiving, faith leaders of all major religions take part in services and programs to increase awareness of donation. OneLegacy staff and volunteers provide information and support for this event.

- ‘Give Thanks, Give Life’ - throughout the year, OneLegacy and its ambassadors support houses of worship by providing a speaker or information for newsletters.

- ‘National Hispanic Heritage Month’ - celebrated from 15 September to 15 October. During this time OneLegacy and its volunteers expand their efforts to educate Hispanics/Latinos about organ donation.

OneLegacy and its Done Vida Ambassadors have also worked with Mexican consulates to provide information to Mexican-origin Hispanics/Latinos through consulate websites, newsletters, Facebook pages, health fairs, meetings with officials and the media. In April 2012, Done Vida California and the Mexican consulate in Los Angeles held the ‘Noche de Celebracion’ gala. The aim of the gala was to inspire the Hispanic/Latino population in Los Angeles to ‘donate life’.

OneLegacy's Media and Communications team members work very closely with the Association for Multicultural Affairs in Transplantation (AMAT). Elena De La Cruz, OneLegacy's Media Relations Specialist, chairs the AMAT Hispanic/Latino Multicultural Work Group (teleconferences for this group are conducted in Spanish). The work group recently created a Spanish/English brochure for the Donate Life America brochure series. This was created as a bilingual brochure as Hispanic families are often a mix of 1st to 3rd generation immigrants with different levels of acculturation and language use at home.

A recent promotion OneLegacy was involved in through their work with the Association of Multicultural Affairs in Transplantation was ‘Inspiring the World to Donate Life Through Asian Media’. This promotion featured partners including the Japan Organ Transplant Network, the Korea Ministry of Health and Welfare, the People's Liberation Army, Red Cross - China and Tzu Chi in Taiwan. Public service radio announcements were created in Mandarin & Korean and television advertisements were created in Chinese (Mandarin and Cantonese). Five organ donation and transplant documentaries were aired in both the US and in Korea. The campaign promoted donation through key community figures such as the celebrated religious hero in South Korea, Cardinal Stephen Kim, whose corneas were donated after his death.
In 2011, the Association of Organ Procurement Organisations (AOPO) signed an agreement with the international charitable organisation, Buddhist Tzu Chi Medical Foundation, which has 80 offices throughout the United States. The Tzu Chi Foundation states the Buddhist view of organ donation is that it is the utmost act of compassion. The Foundation supported organ donation in the US for decades, with OneLegacy in particular, by providing support to Buddhist and Chinese-speaking donor families as well as providing charity assistance and undertaking volunteer and medical training. Through the agreement, the Tzu Chi Foundation will provide further education and training about organ donation to its members, promote donor registration to Asian and Buddhist communities and provide culturally appropriate support to donor families. As an example, both during and following organ procurement surgery, Tzu Chi members chant for the donor, while other members provide support to donor family members. The Tzu Chi Foundation has also held events including an organ donation drive and a donor family appreciation concert.

OneLegacy compiles a regular newsletter entitled 'The Bridge' which highlights OneLegacy activities and also incorporates a Latino section in Spanish. Another short newsletter called 'Donation Pearls for Physicians' provides information to doctors regarding waiting lists and donation and transplantation statistics.

I was also able to meet with staff from OneLegacy's Family Care Services and aftercare departments. Discussion focused on how staff are selected to attend family meetings where donation is to be discussed. The manager of Family Care Services advised that staff may be selected based on ethnicity or language (as OneLegacy has a large group of multicultural and multilingual staff), or based on what the Family Care Services' supervisor determines is the 'best fit' for a family.

An initiative mentioned to me by the Family Services team was the practice of initiating a 'moment of silence' prior to commencing organ retrieval surgery. This provides time for reflection of the generosity of the donor and the potential lives that will be saved.

OneLegacy's aftercare program includes provision of bereavement literature, grief support counselling and referrals, information on writing to transplant recipients, follow-up letters, telephone calls, donor family gatherings, and events to honour and remember donors. OneLegacy generally keeps in contact with donor families for 2-3 years. Following a donation, families are sent an aftercare survey (in English or Spanish) to provide feedback on the donation experience, which the OPO can use to improve practice and/or provide follow up to a family. OneLegacy also hosts monthly support groups for donor families at their Los Angeles office which are open to adults and children and are offered in both English and Spanish.

Families are sent OneLegacy's donor family newsletter 'The Companion' for three years following a donation, after which time they must opt in to continue receiving these. The newsletter contains donor family stories & grief information and provides information about Donate Life community events. OneLegacy also encourages donor family members and recipients to create a quilt square for their 'Bridging Lives' quilt.

Every March, OneLegacy hosts donor remembrance ceremonies throughout Los Angeles and surrounding areas. These ceremonies are titled 'Fields of Gold' and are named after the popular song performed by music artist Sting. Donor families are invited to attend one
ceremony, after which they are invited to participate in various other Donate Life community events. Hospital staff, OneLegacy employees and ambassadors also attend the ceremonies. The 'Bridging Lives' quilt is displayed at these ceremonies and pins/pendants are presented to families who attend.

I was also able to meet with the OneLegacy team member responsible for the creation of the Facebook Donor Family Group. In June 2011, OneLegacy launched a Facebook support group, exclusively for local donor families. This is an invitation-only group which is monitored by OneLegacy aftercare staff, who offer additional support when required. Over 100 donor family members have joined and other OPOs have also created similar groups. Feedback from members has indicated strong support for such a group.

Whilst in Los Angeles, I was provided the opportunity to attend a donation case in a Culver City hospital. This allowed me to see staff from OneLegacy’s Hospital Development, Clinical Services and Family Care teams working together on a case. I noted many similarities between Australia and the USA in the issues that arose during the donation case.

Whilst at OneLegacy I was also given a tour of the incredible OneLegacy Simulation Centre. The centre provides a simulated clinical setting which allows organ donation staff the opportunity to practice skills in organ donor management and situational awareness as well as further develop their critical thinking skills. This state-of-the-art centre is set up within the OneLegacy offices and features a clinical room containing a patient simulator named ‘Bob’. The patient simulator has realistic anatomy and clinical functionality, and has been donation-optimised to allow accurate testing of brain death responses and practice of clinical donor management skills. An adjoining room allows for observation of the scenarios and has video and sound recording capabilities.

I was given the opportunity to participate in a situational awareness simulation with a ‘family member’ of Bob. This was both exhilarating and nerve wracking, and afterwards I was provided an opportunity to review the simulation on video and given positive and constructive feedback. I was left in no doubt of the benefit of such training for both clinical and family services organ donation staff. OneLegacy offers one or two-day organ donor management workshops to other OPOs in the United States and indicated their interest to provide training to interested Australian donation professionals.
Life Alliance Organ Recovery Agency - Miami - Florida

Background

The Life Alliance Organ Recovery Agency (LAORA) is one of four OPOs in Florida. It is located in Miami and services a population of more than 6 million in the six counties of South Florida, and the Commonwealth of the Bahamas. The majority of the population in South Florida identifies as Hispanic or Latino (48%), with Caucasians (28%) and African-Americans (20%) being the other most populous ethnic groups.

Over the past five years, LAORA has averaged 137 deceased donors per year. In 2011, the agency achieved an average of 3.38 organs transplanted per donor (the 2011 US average rate was 3.07).

In 2011, 42% of people in Florida (over the age of 18) were registered donors. The ‘Joshua Abbott Organ and Tissue Donor Registry’ (named after a Florida lung recipient) was created in 2009 and replaced Florida's former registry. Almost 5 million records from the Department of Motor Vehicles (DMV) were imported into the new registry. Florida residents can register to be an organ and tissue donor online or when applying for a driver's licence through a branch of the Department of Motor Vehicles.

Fellowship visit

In my time at LAORA, I met staff working in Donor Family Services, Community and Hospital Services, the Preservation and Surgical Department, Clinical Operations, Communications and Outreach & Quality Assurance and Performance Improvement.

Upon my arrival at LAORA, I was provided a tour of the organisation and then met with the agency’s Medical Director. I was shown how the OPO utilised DonorNet (a modification of UNet) to collect data, view donor referral information and case note logs, as well as assist with allocation. I was advised that this system had been recently updated to allow OPOs to input more data and quickly make multiple simultaneous electronic organ offers.

Staff in the Community and Hospital Services Department provided me with information regarding their multicultural outreach programs. These programs focus in particular on Hispanic/Latino and African-American communities. Staff members from a variety of cultural backgrounds, many of whom speak Spanish, work within this department. Multicultural staff are also members of LAORA’s Board of Directors.

In past years, LAORA set up Hispanic/Latino and African-American taskforces to guide organ donation education in these communities. These have since been dissolved as programs are now integrated into LAORA's community outreach activities. Donate Life Florida also created a ‘Multicultural Initiatives Plan’ in order to target Hispanic/Latino, African-American and other minority communities. This utilised media events (radio, print and local & national television) as well as interviews with donor families and transplant recipients to provide information to these communities and encourage community members to register as organ and tissue donors.
LAORA's Community Education Director recommended the following strategies be considered when undertaking community outreach programs:

- Set up a taskforce with community leaders, corporations and media representatives and create a charter.
- Focus on increasing the understanding of the benefits of transplantation for minority communities. Introduce organ donation by talking about disease prevention and how some diseases get so bad that a transplant may be needed. Then encourage thought about where a transplanted organ may come from. Finally conclude by providing a statement that organs come from people who have agreed to be donors.
- Utilise local media specific to community groups - purchase media spots if you cannot get interviews or free airtime.
- Announce partnerships during key community events and ensure all events of high importance to ethnic communities include Donate Life representation.
- Encourage transplant recipients within multicultural communities to request community participation.
- Offer training to community members/volunteers to enable them to provide accurate information to their communities.
- Train community members to be designated requestors (or assist with the requesting process). In LAORA's experience this has assisted with gaining consent for organ donation from ethnic communities.

Community events in which LAORA participated have included:

- A 'Gospel for Life Concert' - LAORA sponsored this event and a Donate Life speaker was included in the program. Targeting places of worship for African-American communities is viewed as a key strategy for reaching community members.
- The 'Kingdom Day Parade' in memory of Martin Luther King.
- The 'Tournament of Roses Parade' in California. LAORA sponsored a donor family to attend the parade.
- The 'Tiger Walk' - a 5km walk and family fun day.
- The annual 'Luminare Awards Gala' - an event which acknowledges hospitals as well as the clinical, non clinical and community champions in the organ donation field. Awards are presented to inspirational and dedicated supporters of donation.

Like OneLegacy in Los Angeles, LAORA also has a strong Donate Life Ambassadors volunteer program that provides donor families, transplant recipients and other volunteers an opportunity to share their experiences and encourage their community members to become organ and tissue donors. One of LAORA's volunteer programs involves providing education to Department of Motor Vehicles staff and encouraging them to positively answer client questions about donation. Volunteers also give
presentations at schools, churches, government agencies, other workplaces, colleges and health fairs.

Examples of promotional materials used by LAORA

LAORA employees also support workplaces to participate in the ‘Workplace Partnership for Life’ program, which encourages organisations to promote organ and tissue donation. Some of the ways this can be achieved in workplaces is:

- through email and/or payslip messages;
- having a donor family or recipient as a guest speaker;
- inviting employees touched by donation or transplantation to share their story; and
- having a workplace display about donation and giving employees time off work to find out information and register as a donor.

LAORA’s Hospital Services team focuses on implementing policies and guidelines in hospitals, providing education programs to physicians and undertaking educational hospital ‘rounding’ - which entails hospital development staff ‘rounding’ hospitals each week to check if there are potential donor cases, answer staff questions and give out merchandise such as pens or mouse pads.

Hospital services staff also assist during donor cases to ensure real-time resolution of any issues, conduct Donate Life days in hospitals to encourage people to sign on as donors and facilitate hospital ‘Donation Championship Councils’. These councils meet quarterly and include representatives from intensive care, operating rooms and the emergency department. Council members are emailed when a donor case arises in their hospital. They also advocate for maintenance and improvement of donation processes and ensure hospitals comply with CMS regulations.

The Clinical Services Team is comprised of administrators on call, referral responders, donor management coordinators and surgical recovery coordinators. The team members support families at the time of donation, request consent, medically manage organ donors in hospitals, participate in the surgical retrieval of organs and provide education to medical professionals. Administrators on call manage clinical staff and provide advice on donor
cases. Referral responders respond to referrals and provide information to hospital professionals. Donor management coordinators coordinate the donation and manage the donor under the direction of their supervisor and the LAORA Medical Director. Surgical recovery coordinators manage the surgical procurement of organs including preservation and transportation. All donor kidneys procured by LAORA are placed in cold storage before being transferred to a pump which performs machine perfusion. The average time kidneys stay on the pump is just over 24 hours. LAORA staff advised this reduces delayed graft function and acute rejection. Kidneys are also biopsied prior to transplant.

Whilst at LAORA I was able to listen to a Daily Activity Review teleconference (DART), in which clinical and hospital services staff discuss referrals and cases occurring that day. This provides an opportunity to update staff with details of active donor cases, discuss donor suitability and management, as well as to discuss and review consent approaches.

I also had the opportunity to meet several Donor Family Services staff members. The Donor Family Services department offers support to families at the hospital and as part of their aftercare program. Staff members from a variety of cultural backgrounds, many of whom speak Spanish, also work within this department.

Aftercare services offered by this department include grief counselling and referrals, support groups and the provision of resources. Families are sent an aftercare survey to provide feedback on the donation experience, which the OPO can use to improve practice or provide follow-up to a family. LAORA also sends a survey to families who decline donation in order to find out more about their decision.

Like OneLegacy in Los Angeles, LAORA has an invitation-only Facebook support group, exclusively for local donor families. This is monitored by LAORA staff, who offer additional support when required. Almost 60 donor family members have joined the group.

Events undertaken by the Donor Family Services department include:

- The annual ‘Donor Remembrance Ceremony’ held each Spring in Miami;
- The ‘Donor Family Picnic’ - at which donor families are encouraged to share experiences and support one another; and
- ‘Build a Bear’ workshops which donor families are encouraged to participate in.
The Donor Family Services department offers families the opportunity to honour their loved one through the 'Gift of Life' quilt. Several quilts have been completed and these are taken to various community events in order to share donor family stories, increase public awareness and encourage community members to consider donation.

LAORA publishes a quarterly newsletter entitled 'Journeys' which features information about donor family events as well as donor family and recipient stories.

LAORA also has an initiative within hospitals called the 'Tree of Life'. This is a plaque with 'tree leaf tags' containing the names of organ donors from a particular hospital. A tree was chosen as it represents life. Tree plaques are unveiled at a special ceremony, to which donor families are invited, and are displayed in public areas within hospitals. Additional tags can be added to the trees over time.

I was particularly interested in LAORA's policy of allowing donor families and recipients to meet one another. This practice is not currently allowed in Australia. Criteria that LAORA require donor families and recipients to follow, in order to participate in this program, include:

- both parties - the donor families and recipients - must participate in the exchange of anonymous correspondence for a period of six months, with a minimum of 2 letters/cards per party;
- both parties must express through written communication a mutual interest in disclosing contact/identifying information;
- both parties, must review communication guidelines which identify concerns and benefits associated with the disclosure of contact/identifying information and direct meetings; and
- both parties must sign consent forms in order to receive correspondence containing contact/identifying information.

I enquired as to whether many families request such meetings and if there had been any issues by allowing this. It appears only a small percentage of families request personal contact and to date there have not been any problems with those families that have met.

I also had the opportunity to meet with Ken Trachy, a LAORA staff member who undertakes special projects within the OPO. Ken co-founded LAORA in 1978 and was employed as its Director of Education for twenty-one years. During this time he helped create and coordinate public relations campaigns for multicultural audiences. Ken is also a kidney transplant recipient.

Ken discussed his illness and his experiences as a kidney transplant recipient. He initially received a kidney donated by his father, and years later another kidney from a teenage girl who died tragically.

Ken also discussed a grant project, funded by the Health Resources and Services Administration (HRSA), which he oversaw as the Project Director. This was entitled 'A Model Intervention for Increasing Minorities Intent to Donate in Primary Care Centres and Churches in Miami-Dade County'.
The project aimed to increase the number of minority organ and tissue donors (African-Americans, Haitians and Hispanics/Latinos) by increasing both intent to donate as well as family notification of the intent to donate. The project enlisted the support of the African-American Council of Christian Clergy, the Consortium of Haitian Pastors and the Archdiocese of Miami. It also received support from the Centre for Haitian Studies, Haitian media, schools with a large proportion of Haitian immigrant students, the Haitian American Citizenship & Voter Education Centre and the Haitian Neighbourhood Centre. LAORA also enlisted a minority-owned production company to produce advertising. The project focused on targeting barriers including the perceived inequities in the organ allocation system, medical mistrust, and the belief the family had to pay for donation.

Project evaluation showed that it successfully increased knowledge and family discussion about organ donation in all three ethnic groups. However African-Americans were the only group that significantly increased their rate of signing donor cards. The project also concluded that primary care centres were not the ideal place for outreach due to interruptions and the fact that providing brochures alone did not result in behavioural change. Ken believed the partnership with community and religious organisations was an important success factor.

On my final day with LAORA I met team members from the Quality Assurance and Performance Improvement Department. This department ensures the accuracy and timeliness of record keeping and data collection to ensure LAORA complies with regulatory standards. Several staff members showed me through the various types of information they collected including hospital death audits and statistics on the effectiveness of requests for consent.

Yilian Fraga and Lee Wood at LAORA
Washington Regional Transplant Community - Annandale - Virginia

Background

The Washington Regional Transplant Community (WRTC) is the only OPO for Washington DC, North Virginia and Maryland. It services 45 hospitals, 5 transplant centres and a population of approximately 5.15 million people.

As the WRTC works across three different states, it is not possible to accurately calculate the specific demographics of the population serviced by the OPO. Washington DC, Virginia and Maryland have large populations of African-Americans, with Caucasians and Hispanics/Latinos being the other most populous ethnic groups.

Over the past five years, WRTC has averaged 119 deceased donors per year. In 2011, WRTC achieved an average of 2.65 organs transplanted per donor (the 2011 US average rate was 3.07).

In 2011, 64% of people in Virginia, 50% of people in Maryland and 41% of people in Washington DC (over the age of 18) were registered donors. Residents of each of these states can register to be an organ and tissue donor online or when applying for a driver's licence through a branch of the Department of Motor Vehicles.

Fellowship visit

The WRTC has staff who undertake roles in various departments which include Family Services, Recovery Services, Donor Family Support, Hospital Services & Professional Education and Media & Community Education.

Margaret Mead quote on WRTC office wall

I initially met with representatives of the Family Services department and discussed consent approaches with families of different ethnic backgrounds. Whilst each donation case is different, the following points were raised by Family Services team members:

- When requesting consent from a family of a different cultural background it was advisable to have someone from the same cultural group, and/or someone that spoke the same language as the family, attend the family meeting.
• WRTC has multilingual and multicultural staff members within the Family Services department, and are looking to employ a male staff member (appropriate when requesting from Hindu and possibly other families).

• WRTC staff always ensure families understand brain death prior to talking about organ donation. If a family initially declines their consent for donation, WRTC staff will continue dialogue with the family to examine whether their concerns can be addressed at the time.

I spent many hours with members of the Media and Community Education team learning about the services and resources they provide. They discussed WRTC's involvement in activities, including:

• holding an annual 'Race to Donate Life' - held to encourage the community to register as organ, eye and tissue donors;

• participating annually in the 'NBC4 Health and Fitness Expo' which attracts thousands of people;

• partnering with the DC United Soccer League and holding a Donate Life match where young transplant recipients walk out with the players at the opening of the game;

• undertaking activities as part of Donate Life month in April. In 2012, an anchor of a local news program, who is a strong advocate for donation, interviewed a number of people on her program to raise awareness of donation;

• encouraging volunteers to participate in the annual Rose Parade in Pasadena, California;

• participating in the 'National Cherry Blossom Festival' - this festival celebrates the gift of 3,000 cherry trees that the city of Tokyo gave to Washington DC. WRTC had a float in the parade and donor families and transplant recipients participated. WRTC also placed media advertising in local newspapers, linking the delicate life of a cherry blossom with the fragility of life and requesting people consider being donors;

• encouraging faith leaders to participate in the National Donor Sabbath and provide services and programs to educate their congregations about donation and transplantation;

• undertaking activities in August as part of National Minority Donor Awareness Month, including;

  • partnering with 'Eventos VIP Pass' magazine for the 'Festival por la Vida' (Festival for Life). This festival aims to raise awareness of donation in multicultural communities and encourage members of these communities to register as donors; and

  • holding an annual 'Celebracion por la Vida' (Celebration of Life) concert. This is recorded and presented in ethnic media, including radio, press and on a local Spanish-language television show.
The WRTC has also assisted in promoting Donate Life America's campaign ‘20 Million in 2012’. WRTC has supported the campaign in 2012 by:

- providing donor family and recipient stories to media during three weeks of 2012 (one week each for the District of Columbia, Maryland and Virginia). The stories were also posted on Facebook and Twitter;
- participating in the ‘Linking Hands for Life’ promotion. Over one hundred volunteers dressed in blue and green Donate Life shirts near the Lincoln Memorial to link hands for life; and
- working with DMV's to encourage their staff to dress in blue and green Donate Life shirts and participate in ‘Flaunt Your Colours Day’. This assisted in promoting donation to the public and encouraging them to register as a donor while at the DMV branch.

Other points of interest relating to WRTC's Media and Community Education team are:

- they issue a quarterly newsletter ‘Community Pages’ which includes details of their events, presentations, media stories and donor family services;
- they try to ensure correct donation terminology is used by media organisations and provide information on their website in regards to this;
- the WRTC has a very active volunteer program called ‘Friends for Life’. Volunteers or ambassadors are provided with training and assist to promote donation by telling their stories in hospitals, workplaces, churches, DMVs and at many other events;
- the WRTC uses Donate Life America pamphlets in their activities (these are tailored to the community by including photos of local transplant recipients);
- the WRTC encourages people in the community to purchase Donate Life licence plates to help spread the message of organ and tissue donation; and
- the WRTC has a mascot ‘Captain Cardinal’ (the cardinal is the state bird for Virginia). The mascot helps promote donation and is very popular with children.
The Washington Regional Transplant Community offers two scholarships to students. The 'Leslie Ebert - Legacy of Life Scholarship' (named in memory of a young WRTC staff member who passed away) is aimed at high school students and invites them to submit a persuasive essay on organ and tissue donation. Winners are chosen by a panel of judges with cash prizes (including a $5000 first prize) given to the winning entries. The essays form part of WRTC's promotional materials. As part of their efforts to promote donation in the Latino community, the WRTC also offers a 'Done Vida Scholarship'. This is targeted at senior high school or college Latino students and invites them to submit a 2–3 minute video dispelling one of the myths surrounding donation. Winners are chosen by a panel of judges and through public voting on Facebook. Cash prizes (including a $3000 first prize) are given to the winning entries and the videos form part of WRTC's promotional materials.

I was provided the opportunity to present to WRTC staff regarding organ donation in Australia and the Indigenous Education resources developed in the Northern Territory. The challenges faced in the Northern Territory provoked much discussion during this session.

Whilst I was at the WRTC, I had the opportunity to meet with Elling Eidbo, the Executive Director of the Association of Organ Procurement Organisations (AOPO). He provided a summary of AOPO's functions, as well as an excellent overview of the regulation of donation in the United States. Information relating to the discussions in this meeting can be located in the 'Organ and Tissue Donation in the United States' section of this report.

I was also able to meet Jennifer M Porter, a lawyer and three-time cornea recipient. Jennifer discussed her experiences as a recipient and also provided information on the Uniform Anatomical Gift Act. Information relating to discussions regarding this Act can be located in the 'Organ and Tissue Donation in the United States' section of this report.

At WRTC I met with Mary Ganikos, the Chief of the Public and Professional Education Branch in the Health Resources and Services Administration's, Division of Transplantation (DoT). We discussed the DoT's programs which include:

- the 'Workplace Partnership for Life' program, for which HRSA provides kits;
- an organ and tissue donation program for high schools called 'Decision Donation'. The program kit contains educational material, video clips and lesson plans; and
- a link with the 'Hollywood, Health and Society' program (based at the University of Southern California), which provides entertainment industry professionals with accurate information for storylines.
In May 2012, HRSA launched a national campaign, as part of 'Older Americans Month', targeting adults over 50 and encouraging them to register as organ donors. The campaign was developed to dispel the myth that being over 50 is a barrier to becoming an organ and tissue donor. Materials developed for the campaign include a brochure in English and Spanish; radio and print public service announcements and web banners.

HRSA has a very informative website as well as a Facebook site and a mobile application. It also utilises current technology such as a Quick Response (QR) code on its print material. When read by a QR reader on a mobile phone this links to the HRSA website.

The DoT provides many print materials for the public including organ donation information brochures, ‘Faces of Transplantation’ calendars (for African-American, Asian and Hispanic/Latino communities) and ‘Health Passports for Life’ (which provide space for people to record their health information and also contain information on organ donation). They also produce resources for the National Donor Sabbath.
HRSA’s DoT also sponsors the National Donor Recognition Ceremony and Workshop which is held in Washington DC every two years. This ceremony honours organ, tissue, eye and marrow/blood stem cell donors and includes a written program with donor tributes, and a video presentation of living donors and donors whose families are representing them. Families are presented with a Donor Recognition Medal and a Certificate of Appreciation from the Administrator of HRSA. The ‘Patches of Love’ national donor family quilt is displayed at the ceremony. The day prior to the ceremony, a series of educational and support workshops are held for donor families, living donors, their family and friends and for professionals who care for and support donors.

The DoT has funded a grant program for over ten years with many grants being offered for organ and tissue donation initiatives. Current and previous grant programs include:

- **Social and Behavioural Interventions to Increase Organ and Tissue Donation.**
- **Public Education Efforts to Increase Organ and Tissue Donation.**
- **State Donor Registry Support.**
- **Clinical Interventions to Increase Organ Procurement.**
- **Media-based Interventions to Increase Minority Solid Organ Donation.**

I was particularly interested in the minority group grants which we discussed further. In 2004, HRSA funded two-year projects that required grantees to create media and grassroots campaigns focused on minority communities. At least 75% of the funds were required to be spent on media buys. The following is a summary of interventions found to be successful in different minority groups:

- **In the African-American population, projects tended to focus on churches as a setting for community based outreach. Successful projects concentrated on building partnerships with community and professional organisations and sponsoring, and having a presence at, all major events central to the community. Ensuring events had African-American staff and volunteers present was an important success factor.**
Employing transplant coordinators and community outreach workers of cultural similarity was a key part of the successful interventions.

- In the Hispanic/Latino population, ensuring messages were targeted in language was one of the key successful intervention strategies. Placing Spanish language messages in Spanish language stations and utilising Spanish outreach workers (OPO staff or volunteers) were vital to the success of projects. As with the African-American community, it was found to be important to build partnerships with workplaces and community organisations and ensuring a presence at important community events.

- There were only a small number of projects that targeted the Asian community. These projects highlighted the importance of employing culturally similar outreach workers and/or requestors who speak the language of the community.

The minority group grants program found a single, general population campaign was unlikely to improve minority outcomes. It also emphasised that culturally similar requestors have demonstrated a significantly positive impact on consent rates.

Whilst at WRTC I also met with the Donor Family Support team. This team administers the donor family advocacy program. A donor family and community advisory council provides guidance and advice regarding the advocacy program.

Following a donation, each donor family member or living donor is assigned a Donor Family Advocate whom they can contact for support at any time after the donation. Families are contacted for up to two years after a donation. Services and resources provided for donor families include:

- a folder containing bereavement and resource literature (grief booklets, support group information & guides for writing to recipients);

- quarterly bereavement seminars, each covering a different aspect of grief and facilitated by trained professionals;

- an annual donor family gathering - approximately 500 people, including donor family members, transplant recipients and transplant professionals attend this. Donor families are presented with a plant and a remembrance gift during the service of remembrance;

- annual 'Tree of Life' events - held in December at varying locations, donor family members and recipients are asked to hang an ornament in honour of their loved ones to transform an empty tree into a living one; and

- a 'Hope for the Holidays' gathering - this is facilitated by a grief specialist and helps families develop strategies to cope over the US holiday period.

The donor family advocacy program offers families the opportunity to honour their loved one by making a quilt square for WRTC's donor remembrance quilt.
Donor Family Support staff compile a newsletter entitled ‘LifeLines’ which is sent to all families (from nine months post-donation). This contains information on WRTC programs, upcoming events and opportunities to volunteer.

WRTC Donor Family Support staff will assist families if they wish to meet their recipients. They produce a discussion guide for donor families and recipients with information on potential benefits and concerns with making contact. Families must sign a release form if they wish to participate.

WRTC has a ‘Remembrance for Life’ program which helps families let others know, at events such as viewings or funerals, that their loved one was an organ and tissue donor. Some items offered to families at no cost through this program include:

- a framed remembrance certificate for display;
- Donate Life pins and wrist bands which can be placed in a basket at the service;
- brochures about organ and tissue donation; and
- suggestions for an obituary acknowledgement.

WRTC has a ‘Threads of Compassion’ program which encourages volunteers to knit comfort shawls. These are provided to families as a measure of comfort whilst waiting in the hospital.

On my final day at WRTC I had the opportunity to meet with the Recovery Services department. We discussed their system of appointment of clinical staff and the training program provided to these staff. When people apply for positions at WRTC they attend two interviews. In the first interview, a detailed explanation of the position they are applying for is provided (including the onerous on-call responsibilities). Applicants are invited to consider this information and call back within a few days if they wish to proceed to a second interview. At the conclusion of the second interview, applicants spend time with other team members to see more of what positions entail.

Once selected, personnel start at entry level as Clinical Recovery Associates. While in these positions they answer calls, update databases, prepare equipment for theatre, complete chart reviews and, once they are more experienced, attend cases with more senior staff. Clinical Recovery Associates must undertake a training program consisting of lectures, readings, discussions, a research project and exam assessments. The program has twenty-one modules to complete followed by a series of written and oral examinations. Once staff have successfully completed the training, and been in their positions for at least one year, they are then eligible to commence further training to be a Transplant Coordinator. This consists of twenty-six modules of core training and includes practical training in renal perfusion, hospital services and organ allocation. Finally, staff must complete a series of visits, observations, meetings and exams before being able to become a Transplant Coordinator.
With staff at the Washington Regional Transplant Community
New York Organ Donor Network - New York

Background

The New York Organ Donor Network (NYODN) is one of five OPOs in New York. It is located in south-eastern New York and services over 90 hospitals, 10 transplant centres and a population of approximately 13 million people. New York City is the most populous city in the United States and has an extremely diverse multicultural population. The majority of the population identifies as Caucasian (51%), with African-Americans (17%), Hispanics/Latinos (17%) and Asians (8%) being the other most populous ethnic groups.

Over the past five years, NYODN has averaged 273 deceased donors per year. In 2011, the network achieved an average of 2.54 organs transplanted per donor (the 2011 US average rate was 3.07).

In 2011, 18% of people in New York (over the age of 18) were registered donors. New York residents can register to be an organ and tissue donor online or when applying for a driver's licence through a branch of the Department of Motor Vehicles. When registering through the DMV, in addition to being placed on the Registry, a red heart symbol and the words 'ORGAN DONOR' are printed on the licence.

Fellowship visit

The NYODN comprises staff who undertake roles in departments including Clinical Services, Donor Referral and Recovery, Preservation, Organ Allocation, Hospital Development, Donor Family Services, Education and Training, Marketing and Communications, Performance Improvement, Finance, Human Resources and Information Technology.

Upon my arrival at the NYODN, I was provided with a tour of the organisation and then had the opportunity to participate in a case review meeting in which clinical and hospital development staff, as well as performance improvement staff, discussed referrals and cases occurring that day.

I then met with one the managers from the Clinical Services team. The team has four managers, each responsible for a different region and for managing staff including Donor Evaluation Coordinators, Transplant Coordinators and Family Services Coordinators.

Clinical staff progress through a series of tiers before undertaking more detailed responsibilities. Staff are provided with in-house education for an average of six months. Anyone wanting to work as a Transplant Coordinator must pass an examination prior to interview. The exam utilises questions taken from the American Board for Transplant Certification (ABTC) clinical examinations.

We discussed the role and required qualifications of the Transplant Coordinator. This position responds to hospital referrals of potential organ donors and assesses medical suitability (with assistance from the Clinical Manager and Medical Director). They request donation from families, coordinate the donation process, allocate organs to transplant centres and organise the theatre arrangements. They also undertake professional and public education. To work in this area, staff must be registered nurses or physician assistants with critical care experience. They must also possess excellent critical thinking, problem solving and interpersonal skills.
I was provided with a tour of the Donor Referral and Organ Allocation Centre and met staff working in this area. The NYODN also utilises an electronic referral system, which tracks potential donors and the status of each donor case. Once again I was struck by the efficiency of such a system and reflected on its time-saving benefits. Staff employed in the centre are provided with training to allow them to undertake basic donor screening. Should a case progress further, then it is passed onto a more experienced clinical team member. Staff within the centre are also trained to request tissue donation and refer tissue to eye banks, skin banks and heart valve banks. Two quiet rooms within the centre allow for private telephone conversations with family members.

I was also provided with a tour of the organ preservation area where kidneys are placed on mechanical pumps. Whilst on the pumps, kidneys are perfused with preservation fluid and data is collected regarding resistance and flow.

I met with team members from the Donor Family Services department, - some of whom have been personally affected by organ donation or benefited from donation (e.g. one of the staff members is the wife of a donor, a kidney recipient, and the mother of a living donor, while another staff member is a liver transplant recipient). The team provided me with an overview of the services and resources offered to donor families. These include pamphlets containing information specific to different religions, a memory box, bereavement literature, grief support counselling and referrals, information on writing to transplant recipients, follow-up letters, telephone calls, donor family gatherings, and events to honour and remember donors. Families are surveyed 2-3 months after a donation in regards to their experiences and followed up for a minimum of two years post-donation.

The Donor Family Services department oversees a program called 'Sean's Gift'. Named after a young soldier who became a donor, volunteers knit blankets which are provided to donor families while they are waiting at the hospital.

Families are provided the opportunity to honour their loved one by making a quilt square for the NYODN's 'Memory Quilt of New York'.

An annual donor family recognition event is also held in memory of the generosity of organ and tissue donors.

I met with several hospital services managers from the Hospital Development department to discuss their roles. These roles are seen as very strategically important in the donation area. Staff are responsible for a 'portfolio' of several New York hospitals and ensure organ and tissue donation hospital agreements and policies are kept updated. A resource entitled 'Organ, Eye and Tissue Donation - A Guide for Health Care Professionals' is provided to hospital staff by the NYODN. The resource provides information on the role of health professionals in organ and tissue donation as well as some information about the donation process. Hospital staff are also provided with organ and tissue donor referral trigger cards which list clinical triggers as well as a brain death determination checklist and donor management goals.

Members of this team also kindly provided me with an overview of the history of donation in the United States. Of particular interest was a discussion regarding the 'New York Guidelines for Determining Brain Death', which were updated in November 2011 following a review of the guidelines by the American Academy of Neurology.
The guidelines state that after ensuring certain pre-conditions are met, a single, rigorous clinical examination showing that brain function has ceased, following by an apnoea test, is sufficient to determine brain death. In Australia, two medical practitioners with specific experience and qualifications must both undertake clinical testing. New York State law however, requires brain death to be formally certified by two physicians (the physician who performed the examination and another independent physician), neither of whom can be involved in the transplantation procedure in any way. This also corresponds with Australian practice.

Whilst at the NYODN, I was provided an opportunity to attend their monthly Internal Performance Improvement Committee meeting. This meeting involved senior staff from all departments and focused on performance indicators and quality improvement. Performance improvement staff also provided updates on changes to regulatory requirements. I subsequently met with the Director of Performance Improvement and Corporate Compliance who showed me through a number of data reporting systems. Some of the reports I was able to observe provided data on donation rates, referral demographics, organ utilisation rates, hospital performance and staff member consent scorecards. It was apparent that almost any statistical measure required for reporting or quality improvement purposes could be extracted swiftly from the reporting databases.

The NYODN Marketing and Communications team provided me with a presentation detailing their activities and recent campaigns. Throughout the year they participate in:

- **'Black History Month'** - during February each year, the NYODN focuses on increasing the number of African-Americans who register as donors in New York. In 2011, the NYODN partnered with African-American leaders across the New York metropolitan area in the ‘I Am Proud to Be an Organ Donor’ campaign. The campaign focused on the contribution of Dr. Samuel Lee Kountz Jr., an African-American resident physician at Stanford University, who in 1961, was the first physician to perform a kidney transplant between a recipient and donor who were not identical twins. He subsequently went on to perform more than 500 kidney transplants;

- **'National Donate Life Month'** - in April each year, the NYODN organises ‘donor registry drives’ to encourage people to sign-on to the New York State Donate Life Registry. In 2012, they focused their efforts on a DMV campaign, with volunteers and staff placed at 26 DMVs throughout the month. Volunteers told their personal stories of organ donation or transplantation, and encourage customers to register as donors. The NYODN also partnered with local radio stations to promote organ donation through on-air radio announcements and social media;

- **'National Minority Donor Awareness Month'** - each August, the NYODN encourages their diverse community to register as organ and tissue donors;

- **'National Hispanic Heritage Month'** - in September/October each year, the NYODN encourages people from Latino communities to register as donors. They also highlight the general willingness of Hispanic people to donate, but the low number of Hispanic people on the register and the great need for more organ donors from this population; and
- **'National Donor Sabbath’** - in November, the NYODN encourages all religious leaders to educate their communities about the critical shortage of organ, tissue and eye donors in New York.

New York Organ Donor Registry sign-on forms are provided in many languages including Spanish, French, Korean, Chinese and Russian. In April 2012, in an effort to register more New Yorkers as organ donors, an online DMV enrolment system was introduced. This enabled people to instantly enrol online utilising secure electronic signatures instead of using a paper system. As a further means to encourage New Yorkers to register as organ and tissue donors, the NYODN recently obtained permission to include organ and tissue donor enrolment as part of voter registration forms. This provides an opportunity for people to sign onto the register prior to the November Presidential election. NYODN volunteers assist with this campaign by setting up information displays in public parks, including Central Park, Union Square and Washington Square Park, as well as in busy areas such as Penn Station and Grand Central Station.

In June 2012, a bill 'Laurens Law' was signed to encourage New Yorkers to register as donors when applying for or renewing their licence. Whilst previously being an optional question, a response is now required to the 'Would you like to be added to the Donate Life Registry?' question. The bill was named after Lauren Shields, a twelve-year old girl who received a heart transplant in 2009.

The NYODN utilises social media, including Facebook and Twitter, in its efforts to promote donation. Its Facebook site has over 30,000 members. The NYODN recently held a 'Think You’re Hollywood?' online video contest asking people to produce a short commercial to encourage people to sign the donor registry. The winner was chosen via public voting and received a trip for two to California, including passes to the Rose Parade and Rose Bowl.

The NYODN has produced a number of posters and resources to promote organ and tissue donation. Several of these were shown to me as part of a presentation. Examples of these are included below.
Recently the NYODN launched a public advertising campaign with the slogan ‘It Kills New Yorkers to Wait in Line’. This hard-hitting campaign features television advertising as well as print media. A poster from the campaign is shown below.
The NYODN tries to ensure correct donation terminology is used by media organisations and provide ‘Tips for Sensitive Language’ in its media kits and on its website.

Linda Bowes and Lee Wood at the NYODN offices
South Dakota State University and South Dakota Lions Eye & Tissue Bank

To conclude my Fellowship studies, I travelled to the Midwest of the United States to Brookings and Sioux Falls in South Dakota. I was interested to learn more about organ and tissue donation research and educational interventions being undertaken with American Indians by the South Dakota State University (SDSU) and the South Dakota Lions Eye and Tissue Bank (SDLETB).

Notable facts and information:

- American Indians comprise almost 1.0% of the population of the United States (3.1 million people). South Dakota has one of the largest populations of American Indians at almost 9% of the population (approximately 60,000 people).

- American Indians suffer from disproportionately high rates of diabetes, kidney disease, heart-related diseases, cirrhosis and other liver diseases. These conditions are known to increase the likelihood of end-stage organ failure. Type II diabetes is 4-8 times more prevalent in American Indians than in the general community and End-Stage Kidney Disease (ESKD) is 3-4 times more prevalent than in the general community.

- American Indians and Alaskan Natives account for approximately 1% of patients on the organ transplant waiting list, although this number is likely to increase.

- Research at John Hopkins University in Maryland found that American Indians are three-times more likely to find a match from the same ethnic group.\(^3\)

- Anecdotal evidence shows American Indians are significantly less likely to consent to deceased donation than other racial or ethnic groups. The majority of American Indian donors are living donors.

- Cultural beliefs and values related to death and spirituality are likely to influence how people make decisions about organ donation. Research with American Indian adults living in Minnesota and North & South Dakota, identified beliefs that entry into the spirit world is dependent upon a body being intact.\(^4\)

- Direct conversations about death may be culturally inappropriate in some American Indian groups.

- A lack of compatible organs for American Indian patients can add to longer waiting periods for transplantation and contribute to higher death rates.

SDSU and SDLETB research and interventions

The following information relates to projects funded through the Health Resources and Services Administration (HRSA), Division of Transplantation (DoT).

Nancy Fahrenwald, Associate Professor at SDSU’s College of Nursing, was the lead investigator for the projects. She worked in collaboration with staff from the SDLETB, as well as with a community advisory council made up of individuals from various tribal communities.
Nancy first became interested in researching organ donation in American Indian (AI) tribes following a meeting with Christine Belitz, the former Executive Director of the SDLETB. The SDLETB wanted to apply for funding, available through the HRSA DoT grant program, which encouraged research into social and behavioural interventions to increase organ and tissue donation. The SDLETB was advised by HRSA that whilst their project had merit, they needed to have a researcher as part of their team in order to receive funding. While searching for a researcher, Christine was provided with Nancy's details. After an initial meeting, Nancy was so keen to be part of the project she cancelled her vacation leave and wrote what was to become one of a series of successful grant applications.

The initial study Nancy undertook, aimed to discover the socio-cultural patterns that influenced decisions about organ and tissue donation among American Indian adults. Whilst Nancy helped to carry out the research component of the study, she received assistance from a tribal college student (with funding provided through the NIH), as well as advice from the community advisory council comprised of members from the tribal community. The community-based participatory research study was undertaken with twenty-one members of the Oglala Lakota Sioux tribe on the Pine Ridge Indian Reservation in South Dakota. Key tribal leaders gave permission to conduct the research and helped choose research instruments and subsequent interventions. Face-to-face interviews were conducted with participants using open-ended questions and these interviews were recorded. Some of the participant comments during the study included:

"I want to be a donor. I don't think they would want any of my trash. Who wants to sell ugly arteries?"

"If you die up here they don't look at those things. They don't look at your driver's licence. They just send you to the mortuary."

"Who cares what happens to my body after I die? I don't care one way or the other. If there's someone who needs my organs, sure, why not, my soul will be gone anyway."

Five key themes emerged from the research, these being:

- there was uncertain knowledge about organ and tissue donation;
- the prevalence of diabetes within the community was acknowledged by every participant;
- traditional cultural beliefs (such as needing to be whole when entering the spirit world) were acknowledged, although there was recognition that these beliefs may have to be revisited in light of the health crisis facing the Tribe;
- participants lacked confidence that their local health system would allow donation; and
- participants wanted targeted outreach education with information disseminated through their families, tribal leaders and the media.
Further the study found it was important that:

- education programs respect traditional beliefs while still providing information about the option of donation;
- educators need to connect donation discussions with stories of community members affected by diabetes and donation/transplantation; and
- healthcare systems (hospitals and OPOs) need to approach American Indian potential donor families with some understanding of traditional beliefs and communication processes.

With respect to the latter point, Nancy commented that responses to requests for donation from American Indian families are not likely to be a straightforward 'Yes' or 'No'. Rather responses will be provided after a process of thinking, talking with community members and revision of information (in a longer time-frame than the general community).

Subsequent to the initial study, SDSU successfully applied for additional HRSA DoT funding to design and evaluate an educational intervention aimed at increasing intention among American Indians to become organ or tissue donors. The study and intervention was called 'Sharing the Gift of Life'. Nancy and the community advisory council designed the study and approach which used pre/post-test design and a community-based participatory approach. The study was based on the 'Transtheoretical Model of Behaviour Change' which assesses an individual's readiness to act on a new healthier behaviour, and provides strategies to guide the individual through stages of change.

The study participants included 1580 adults from four Northern Plains reservations, these being Pine Ridge, Rosebud, Cheyenne River and Sisseton-Wahpeton. Only limited demographic data was collected (as advised by the advisory council) to reduce the burden on participants and build trust that this project wasn't like others that 'researched a community but gave nothing back'. Prior to the study, analysis showed that 55% of participants were not thinking about being a donor (pre-contemplation stage), while 45% were considering it (contemplation stage). Comparison counties (where no intervention took place) were used as control groups.

Two American Indian advertising firms helped develop the print and video educational materials to be used in the project. As per the advice of the advisory council, the materials were designed for an English language speaking audience. Both the community advisory council and a group of community participants evaluated the materials. Following this revisions were made, including altering the pronunciation of traditional language in the video. A point of interest raised by the advisory group was that the focus on particular time intervals in donation conflicted with their cultural perceptions of time.

The educational interventions and materials developed by SDSU and the advisory council were based upon the cultural traditions of story-telling and gift giving. During the educational interventions, an outreach coordinator provided information to tribal members either individually or in groups at key gathering places. During these education sessions, stories were told about members of the community that either needed an organ transplant or had received one. The revised educational materials were used to provide further information and promote donation.
Evaluation of the intervention found that approximately 57% of participants progressed in their stage of motivational readiness to become a donor. Of these, 26.5% moved from pre-contemplation to contemplation, 19.4% moved from contemplation to preparation and 11.1% of participants moved from the preparation to action stage by discussing donation with their families and signing on to the state registry. A further result of the study was the increased discussion it generated within the communities.

Resources developed for educational interventions with AI tribes

Nancy believes the success of the projects can be attributed to three factors, these being:

- community engagement which began with tribal leaders, medicine men and health providers before planning the study;
- application of local knowledge in the understanding of deceased donation - telling local stories was a key factor in education; and
- the investment of community members - i.e. tribal members participated in the community advisory council which shaped and guided the interventions.

Nancy also received funding for a third research project titled 'Tribes Sharing Life'. This measured motivational readiness to become a deceased organ and tissue donor among American Indian college students. The project was conducted at tribal colleges in North and South Dakota, Minnesota and Montana. It compared the effectiveness of classroom-based education (utilising educational resources) with static displays of print materials promoting the project's web-site.

Evaluation of the project found that both strategies were successful in increasing motivational readiness to be an organ and tissue donor, however interpersonal communication, through the oral tradition of storytelling, was the most effective in motivating the students. Overall 61% of participants progressed in their stage of readiness to become a donor and 20% enrolled in a state registry. A further result of the project was an increase in the number of American Indian students that utilised social networking sites to spread messages about the need for organ donation.
Nancy provided a number of statements in regards to the outcomes of her research, these being:

- whilst the messages and strategies arising from the studies cannot be generalised across communities, it does appear that culturally-focused deceased donor educational interventions are of benefit to communities;

- when working with communities it is important to spend time establishing trust, showing commitment, building relationships and discovering the community's priorities and concerns;

- interpersonal communication, through the oral tradition of storytelling and involving community members, is one of the most effective ways of increasing knowledge and behaviour in tribal communities;

- involving health care providers from communities in education efforts is very important as it is these people who are known to and trusted by the community;

- even though there are traditional beliefs about the body in some communities, there is a recognition of the need to bridge traditional and contemporary beliefs; and

- communities can find ways to honour traditional beliefs, such as prayers and rituals, when the body is not intact.

Nancy commented that she had received comments from individuals to the effect that 'with limited health dollars, how can you advocate for transplantation (a costly procedure) when people don't even have access to basic medical care?'. I found her response to be particularly relevant and summed up my reasons for undertaking the Fellowship. She said "It isn't a cost issue but an ethical one - people from all cultures should have access to information and the ability to make their own decisions" (N. Fahrenwald, personal communication, 31 July, 2012).

Nancy is currently the principal researcher and/or investigator in two further research studies focused on American Indians and organ donation. These focus on providing education about living and deceased donation, and investigating barriers to transplantation for the American Indian community.
While in South Dakota I was able to visit the South Dakota Lions Eye and Tissue Bank (SDLETB) in Sioux Falls to learn more about their work and share information regarding American Indian and Indigenous Australian organ donation awareness programs.

Upon my arrival at the eye and tissue bank I met employees Gail Ries and Joan Hammond and received a comprehensive tour of the agency's facilities. I also met a number of additional staff members.

The SDLETB provides both eye banking and tissue banking services. They retrieve donation referrals primarily from hospitals and occasionally from funeral homes, coroners and hospices. Retrieval of eye and other tissue can occur in hospitals and other settings, or within the purpose-built operating rooms at the SDLETB. In 2011, the bank retrieved tissue which enabled over 660 corneal transplants and more than 6000 tissue transplants.

Following retrieval, corneas are evaluated at the bank, and once deemed medically suitable, they are provided to surgeons for transplantation. Tissue is packaged and sent to a tissue processing facility where it is medically evaluated, processed into transplant grafts and released for transplant.

Donor families are also able to consent to the donation of their loved one's body for the purpose of medical education. The SDLETB provides a series of anatomy and physiology courses for emergency medical technicians, paramedics and other medical staff.

Families receive comprehensive follow-up and bereavement support after a donation. This includes telephone support, literature on grief and bereavement, details of donation outcomes and the opportunity to attend donor memorial dinners and luncheons. Families can also submit a quilt square to be included in the SDLETB donor memory quilt.

Whilst at the SDLETB, I had the opportunity to meet Karla Abbott, a member of the Cheyenne River Lakota Sioux tribe and a nursing instructor at Augustana College in Sioux Falls. Karla was also a member of the community advisory council which assisted with the research and education projects, mentioned earlier in this section.
I was able to sit with Nancy, Karla, Gail and Joan to discuss our respective organ donation education programs focused on American Indian and Indigenous Australian populations. These discussions highlighted many similarities between the cultures and reinforced our desire to continue to work in this area.

Karla Abbott, Nancy Fahrenwald, Joan Hammond and Lee Wood with resources developed for American Indian populations
Conclusions and Recommendations

My Churchill Fellowship provided me with an invaluable opportunity to travel overseas and learn more about strategies to engage culturally and linguistically diverse (CALD) populations to increase donation knowledge, intentions and transplantation rates in these populations. An additional benefit of my Fellowship was the opportunity to enhance my understanding of organ and tissue donation programs in the United States.

Recommendations

Increasing donation rates in multicultural populations in Australia

- Increase the number of CALD employees within the organ and tissue donation sector.
- Consider the use of trained CALD volunteers in consent conversations with CALD families.
- Expand multicultural volunteer networks both locally and nationally.
- Hold a national forum with key stakeholders focused specifically on identifying multicultural issues in the donation and transplantation field and strategies to address these.
- Implement a national day focused specifically on increasing awareness of donation issues in CALD communities.
- Continue to fund grant programs for projects relating to organ and tissue donation and transplantation in CALD groups.
- Increase promotion of donation at key cultural and religious events, festivals and national days.
- Utilise CALD donor families and transplant recipients to enhance education activities undertaken.
- Further expand information and resources available to CALD populations on the DonateLife website.
- Ensure promotional materials and advertising targeted at CALD populations contain images of people from these communities.
- Establish a representative community advisory council when undertaking projects with CALD communities to participate in the planning, implementation and evaluation of activities.
- Spend sufficient time establishing trust, showing commitment, and building relationships with CALD communities when planning and undertaking educational activities.
- Involve community-based health care providers in education activities targeting CALD populations.
General recommendations for the Australian organ and tissue donation sector

- Move towards increased recognition of 'first person' consent in conversations with potential donor families.
- Continue with the implementation of an electronic donor referral system in Australia.
- Further the network of donor family and recipient volunteers and provide consistent training to these groups.
- Develop nationally consistent training programs for clinical staff (in addition to the consent training currently being undertaken in Australia).
- Consider the examination and potential implementation of nationally consistent legislation for organ and tissue donation.
- Continue to use and promote social media in donation awareness and education activities.
- Consider creating private donor family support groups utilising social media.
- Develop additional nationally consistent mementos for donor families such as envelopes for locks of hair and quality paper for handprint impressions.
- Consider holding a national recognition ceremony for donor families and recipients and/or developing a national memorial garden or monument.
- Implement colour-coded and waterproof organ packaging labels.
- Add ‘Tips for Sensitive Language’ to the media section of the DonateLife website.
- Continue to use measures other than donors per million population to measure effectiveness of programs.
- Utilise Quick Response (QR) codes on promotional materials and link these to the DonateLife website.

Implementation and Dissemination

- Distribute Fellowship report to colleagues in the organ tissue donation sector in Australia and overseas.
- Present findings to colleagues at a local level.
- Utilise knowledge gained to further develop educational programs for Indigenous Australians, particularly in the Northern Territory.
- Present findings to senior staff of the Australian Organ and Tissue Authority (AOTA), State Medical Directors and jurisdictional colleagues at national meetings.
- Nominate as a member of the proposed AOTA multicultural communication committee.
Glossary of Abbreviations

AATB - American Association of Tissue Banks
ABTC - American Board for Transplant Certification
AHW - Aboriginal Health Worker
AI - American Indian
AMAT - Association for Multicultural Affairs in Transplantation
ANZDATA - Australia and New Zealand Dialysis and Transplant Registry
ANZICS - Australian and New Zealand Intensive Care Society
ANZOD - Australia and New Zealand Organ Donation Registry
AODR - Australian Organ Donor Register
AOPO - Association of Organ Procurement Organisations
AOTA - Australian Organ and Tissue Authority
ATBF - Australasian Tissue and Biotherapeutics Forum
ATCA - Australasian Transplant Coordinators Association
CALD - Culturally and Linguistically Diverse
CDC - Centre for Disease Control
CMS - Centres for Medicare & Medicaid Services
DMV - Department of Motor Vehicles
DoT - Division of Transplantation
DPMP - Donors Per Million Population
EBAA - Eye Bank Association of America
EBAANZ - Eye Bank Association of Australia and New Zealand
ESKD - End-Stage Kidney Disease
FDA - Food and Drug Administration
HHS - Health and Human Services
HLA - Human Leukocyte Antigen
HRSA - Health Resources Services Administration
LAORA - Life Alliance Organ Recovery Agency
MOTTEP - Minority Organ Tissue Transplant Education Program
NAAG - National Association Of Attorneys General
NATCO - North American Transplant Coordinators Organisation
NHMRC - National Health and Medical Research Council
NIH - National Institutes of Health
NT - Northern Territory
NYODN - New York Organ Donor Network
OMH - Office of Minority Health
OPO - Organ Procurement Organisation
OPTN - Organ Procurement and Transplantation Network
OTDA - Organ and Tissue Donation Agency
SDLETB - South Dakota Lions Eye & Tissue Bank
SDSU - South Dakota State University
SRTR - Scientific Registry of Transplant Recipients
TGA - Therapeutic Goods Administration
TNA - Transplant Nurses Association
TSANZ - Transplantation Society of Australia and New Zealand
UNOS - United Network for Organ Sharing
US - United States
WRTC - Washington Regional Transplant Community
References

The majority of the information contained in this report was obtained through personal observation and the multiple conversations I had with people during the period of my Fellowship studies.

**Australian Statistics**

Statistics regarding Australian donation rates, waiting list figures and public survey responses can be found at the following websites:


Statistics regarding Australian population figures can be found at following website:


**United States Statistics**

Statistics regarding United States donation rates and waiting list figures (in the general population and in minority populations), as well as organs transplanted per donor, and public survey responses can be found at the following websites:

http://www.unos.org/

http://optn.transplant.hrsa.gov/

http://www.srtr.org/

http://organdonor.gov/whydonate/minorities.html

http://www.hrsa.gov/gethealthcare/conditions/donation.html

http://minorityhealth.hhs.gov/templates/content.aspx?lvl=3&lvlID=12&ID=7988

Statistics regarding US state donor registry numbers can be found at the following website:


Statistics regarding United States population figures can be found at following website:

http://www.census.gov/
OPO websites

Further details in regards to the OPOs I visited during my Fellowship studies can be found on their websites:

http://www.legacyoflifehawaii.org/
http://www.onelegacy.org/site/index.html
http://surgery.med.miami.edu/laora
http://www.beadonor.org/
http://www.donatelifeny.org/

Journal articles


