



Canberra Region Kidney Support Group

Kidney News

The views expressed in this newsletter are not necessarily those of the CRKSG

Organ Donor Awareness Week

Because this issue will be published around about the time of Organ Donor Awareness Week the content will be devoted largely to organ donation.

Organ Donor Awareness Week is held each year in February throughout the nation. This year it is between 17th February and 24th February. Organ Donor Awareness Week in the ACT was officially launched on 14th February 2008 at the Parliament House by Senator the Hon. Jan McLucas, Parliamentary Secretary to the Minister for Health and Ageing.

During this week people who have not already registered as a donor are encouraged to do so. This encouragement is provided through volunteers manning stalls in the major shopping centres in the ACT providing information and giving passers-by the opportunity to complete a registration form on the spot.

The speakers at the launch included in addition to Senator McLucas, Senator Gary Humphries, Anne Cahill Lambert, Chair of the Gift of Life Foundation in the ACT, and a representative of the wife of Terry Connolly. Terry passed away in September last year and his corneas were donated.

All of the speakers had a fairly common theme. They all urged registration as an organ donor and to speak to family about this.

Senator McLucas told the gathering that during the next week about 10 Australian families will have to deal with the sudden death of a loved one in circumstances where that person could be an organ donor. Eight of those families will be asked to agree to organ donation. Three or four will agree.

Senator McLucas also pointed out that our waiting lists for organ donation are gradually growing. Australia has one of the lowest rates of organ and tissue donation in the Western world. Last year, just 198 people became organ donors Australia wide. The gifts from these donors gave another chance of life to 626 people of all ages but many more than this suffered or died because of the lack of availability of organs from matching donors.

The availability of donated organs has stalled in Australia. Some of this can be attributed to the better outcomes in other areas. Not the least of these is the reduction



l to r: Senator Jan McLucas, Senator Gary Humphries, Anne Cahill Lambert

Contents:

Organ Donor Awareness Week	1
Rudd Government acts to Lift Organ Donation Rates	3
What can the Group do to Generate Interest?	4
Kidney Health Australia Welcomes Rudd Commitment on Indigenous Health	4
Calendar of Events	5
Should We Have an Opt-In or Opt-Out Organ Donor System?	5

(Continued on page 2)

(Continued from page 1)

in the road toll, better treatment for other illnesses such as hypertension and high blood cholesterol, the large reduction in the number of smokers, etc., resulting in fewer deaths.

Senator McLucas also said, “It is through the compassion of people such as yourselves and your loved ones that others are given the opportunity for a second chance at life. I sincerely thank you for your compassion, thoughtfulness and courage in considering others at a time of such enormous personal loss. I am sure that most Australians would take a similar decision, if they took the opportunity to think through this issue and acted on their goodwill.

So this week especially, I encourage everyone in the ACT to talk to their families about their personal wishes regarding organ donation.

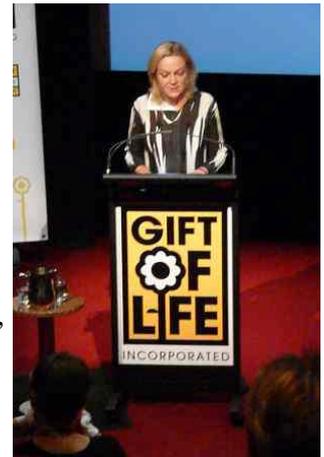
Discussing this decision with the family, partner or close friends is an essential part of the process. Because it is family or other loved ones who finally give permission, and they need to know that they are carrying out the wishes of the person they have lost.

Do they want to give the gift of life? If the answer is yes, and it nearly always is, then I urge everyone to put that wish into action by signing up to the Australian Organ Donor Register. Please don’t leave it until it is too late”.

The Support Group urges all readers, irrespective of your state of health and who have not already done so, to register as organ donors. The Group fully supports the call by Senator McLucas to register as donors.

The full text of Senator McLucas’ speech can be found via the Newsletters page of the Group’s website, <http://www.crksg.org.au/>.

Anne Cahill Lambert, Chair of The Gift of Life Foundation in the ACT also gave a very moving speech on organ donation or the lack of it. She mentioned some cases in point. For example baby Cordelia who is waiting for a liver transplant and a young girl called Annette who was the ACT’s first organ donor. Anne finished with these words:



Senator Jan McLucas



Anne Cahill Lambert

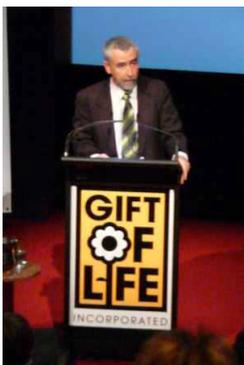
“At the moment there are significant numbers of people who are dying who could be organ donors. I’ll bet they have no objection, but because families haven’t discussed it, consent is not provided. For every potential donor whose relatives or others, including coroners, refuse permission, another three people on the transplant waiting list are given a death sentence.

I’ve told you a number of life stories today from our world here in Canberra. It’s just as bad, if not worse, across Australia. Have things changed since little Annette’s kidneys were donated 33 years ago? We need the brightest brains across Australia who will look at the problems, harness the community as partners, and improve things dramatically.

So this year, and especially today on Valentine’s Day, think about matters of the heart. Think about others. Think about kidneys, lungs, livers. Have a chat with your family. Please enrol on the organ donor register and talk to your family so that everyone is clear. Start a conversation with others about the opt out system. And encourage politicians to support a national summit into organ donation. Serious action is required if we are to improve our organ do-

(Continued on page 3)

(Continued from page 2)



Senator Gary Humphries

nor rates if Cordelia is to survive the ravages of being dealt a bad hand”.

Gary Humphries also spoke about lobbying colleagues on looking into an opt-out donor system rather than the present opt-in. He said he would be writing to his parliamentary colleagues in the next few days canvassing such ideas.

Anne Watchirs spoke on behalf of her sister Helen, Terry Connolly’s spouse, about organ donation and the effects it has on family. For example she said that the family had been able to draw strength from the fact that his death followed his approach to life — he made a positive difference to individuals and society.



Anne Watchirs

The Donor Awareness Week walk this year will be called the Terry Connolly ORGANised Walk.

Rudd Government acts to Lift Organ Donation Rates

The Australian Government would immediately begin work on a range of possible activities to increase the rate of organ and tissue donation, the Parliamentary Secretary to the Minister for Health and Ageing, Senator Jan McLucas, said today.

Senator McLucas said she received the final report of the National Clinical Taskforce on Organ and Tissue Donation last night. “The report contains 51 recommendations to improve our donation and transplantation system.”

“I have assured the taskforce members that I will be carefully considering those recommendations and discussing them with my state and territory colleagues in light of Australia’s low rate of donation.”

“I am acutely aware of the need to improve the system, and to do more to encourage people to register their wishes and discuss them with their families.”

While Australia has one of the best records in transplantation outcomes in the world, more than 1,800 Australians are waiting for a transplant at any given time owing to a shortage of donors, Senator McLucas said at the launch of Australian Organ Donor Awareness Week in Canberra, organised by the advocacy group Gift of Life.

Australia’s organ donation rate has hovered around 200 donors per annum for many years. For every 10 per cent increase in organ donors Australia would be able to change the lives of about 70 people more a year, plus many others through tissue donation.

“More than 90 per cent of Australians support the idea of organ and tissue donation, but we have one of the lowest rates of donation in the Western world. The challenge is to convert that support into action,” Senator McLucas said.

“Firstly, by correctly registering their consent on the Australian Organ Donation Register, which is administered by Medicare Australia, and discussing that decision with their families, people can register online at the Medicare Australia web site, www.medicareaustralia.gov.au, call Medicare on 1800-777-203, or visit their local Medicare office.”

“Secondly, by ensuring that there are procedures in our hospitals to maximise the potential for donation to occur. To support this, the Australian Government has confirmed that funding for the National Organ Donor Collaborative will continue until at least June 2009. The collaborative involves training teams in 26 hospitals across the nation in ways in which donation rates can be improved.”

What can the Group do to Generate Interest?

We have had only a small number of responses to the questionnaire that we sent out a few months back. At first look it appears that the response sample may be too small to be able to come to any definitive decisions. Yvonne, who originated the questionnaire, was not able to attend the last meeting so there has been no in-depth examination of the responses, although a number did suggest having meetings on weekends.

What else can we do? Perhaps readers might like to write to the Group with suggestions and we could perhaps run a "Letters to the Editor" type column. Write and let us know what you think. Letters should be addressed to — Newsletter at the address shown on the back of this newsletter. Email responses could be sent to newsletter@crksg.org.au.

We could then perhaps publish some (or all) of these letters/emails. We envisage the letter would be published showing the writers name and suburb. Your full details would not be published. If you have a reason to do so, you could also ask that your name not be published.

Kidney Health Australia Welcomes Rudd Commitment on Indigenous Health

Kidney Health Australia today welcomed the commitment by the Federal Government to tackle the health issues facing Indigenous Australians with a concerted effort to close the seventeen year life expectancy gap between Indigenous Australians and the rest of the community.

Anne Wilson CEO of Kidney Health Australia said, "The overall death rates from Chronic Kidney Disease (CKD) are up to ten times higher in the Aboriginal and Torres Strait Islander communities compared to the rest of the Australian community.

"The incidence of kidney failure is increasing in the Aboriginal population at a faster rate than in non Aboriginal communities."

Ms Wilson said that the public statement and commitment on resources to tackle the health issues of the Indigenous communities as part of Prime Minister Rudd's "Sorry Statement" is a major signpost to the people in the front line of combating chronic diseases that the Federal Government is looking beyond the band-aid approach of the past.

Medical Director of Kidney Health Australia Dr Tim Mathew said, "Greater prevalence of CKD in some Indigenous Australian communities is due to the traditional high risk factors including diabetes, high blood pressure and smoking.

"This can be compounded due to increased levels of poor nutrition, high alcohol use, streptococcal throat and skin infection, and socio economic disadvantaged living conditions which makes the Federal Government commitment to housing an important step in chronic disease prevention.

"Chronic Kidney Disease (CKD) is often referred to as the "silent killer" as 80 -90% of kidney function can be lost before an individual experiences any symptoms.

"The latest research has recognized kidney disease is a "disease multiplier". It causes death in many people with diabetes and hypertension and predicts the development of a cardiovascular event."

Calendar of Events

Support Group Meetings.

When: Quarterly on second Tuesday of each month.

13th May 2008 and 12th August 2008.

Where: The Pearce Community Centre
Building 1, Collett Place
Pearce ACT 2607.

When: 7:30 pm.

All welcome

Should We Have an Opt-In or Opt-Out Organ Donor System?

There was a report in the Sunday Canberra Times (p4. 17 Feb 08) stating that a national taskforce has spent 12 months considering ways to boost Australia's flagging organ donor rate. This taskforce has apparently rejected the introduction of an opt-out or presumed consent donor system.

Some questions come to mind about this taskforce. Who were they? What were their terms of reference? To whom did they speak? Did they advertise for community input? Why have they rejected the idea of an opt-out system?

We know that they were called the National Clinical Taskforce on Organ and Tissue Donation but we still don't know who they were. One wonders how many of this taskforce is waiting for a transplant, has had a transplant or has a family member who is waiting or has had a transplant. I suspect none of them has any connection to anyone that needs a transplant or has had one.

If the Taskforce thinks an opt-out system causes some sort of ethical dilemma, why hasn't it been an insurmountable ethical problem for a number of European countries? The Sunday Times article also mentioned that where these European countries have in the past introduced an opt-out system, the numbers of donors have increased dramatically. For example, an opt-out system was introduced in Austria in 1982 and by 1990 the number of donors had quadrupled. Similarly, in Spain the donor rate doubled after introducing an opt-out method in 1989.

In Australia the donation rate is appalling. In 2007, in the Canberra region there was only one donor. Overall the donation rate in Australia is something like 10 per million of population giving a rate of perhaps 200 donors per annum.

There are nearly 2000 on the ever growing waiting list. One can assume from this, if there are no new additions to the list or if the new additions just replace those dropping off, it will take something like 10 years, or perhaps more, to satisfy the need. If the Austrian result were to be duplicated in Australia with the adoption of an opt-out system the donation rate would increase dramatically. We could expect the increase to be something in the order of 30 per million bringing the total up to 40, giving us around 800 donors per annum and perhaps going close to wiping out the waiting list in substantially less than 10 years, perhaps in as little as five or six.

What do our readers think about opting out rather than opting in? Write to us at the Newsletter address mentioned on the previous page.

Please be aware that the opinions expressed here are mine.

John Kelly

PO Box 5051
Garran ACT 2605

Phone: 02 6290 1984
E-mail: crksg@shout.org.au
Web: http://www.crksg.org.au



MEMBERSHIP APPLICATION/RENEWAL

Canberra Region Kidney Support Group Inc
PO Box 5051 GARRAN ACT 2605.
ABN: 77 396 063 641

Last Name: **First Name:**

Address:.....

Email:

Phone No:

I would like to make a voluntary donation to CRKSG for the amount of: \$..... Membership is free. All donations \$2 or more are tax deductible. Cheque/Money Order payable to CRKSG Inc. Please accept this application for membership of the Canberra Region Kidney Support Group Inc.

Signature: **Date:**.....

Post Form to:

The Treasurer
Canberra Region Kidney Support Group Inc
PO Box 5051
GARRAN ACT 2605.

NOTE: This form may also be used to notify a change of address/contact details.