



ACT  
Government  
Health

THE RENAL ADVISORY MEETING NEWSLETTER



# THE RAM PAGE

- FEBRUARY 2016 -



- PRINTED QUARTERLY -

## IN THIS ISSUE

- ◆ *Tuggeranong Dialysis Centre*..... *page 1*
- ◆ *Organ Donation in Australia* ..... *page 2*
- ◆ *ACT Quality in Healthcare Award* ..... *page 3*
- ◆ *Introducing consumer reps* ..... *page 4*

## TUGGERANONG DIALYSIS CENTRE

The Diaverum Tuggeranong Dialysis Clinic is a 12 chair unit, conveniently located in the southern Canberra suburb of Greenway within the Tuggeranong Community Health Centre. It is opposite the Tuggeranong Hyperdome shopping centre and the bus interchange. There is a taxi rank right outside the Community Health Centre and there are nearby leisure centres, parklands, clubs, restaurants and schools.

It has been an amazing 8 months at the Tuggeranong Dialysis Clinic. The time has flown! As expected with a new clinic there have been challenges along the way but I am pleased that in the main staff, and patients have embraced changes positively. I would like to congratulate all staff and patients on their positive outlook in the transition of moving to a new clinic and also to the community spirit that is evolving being closer to home and family. Moving forward into 2016, we have a new Patient Consumer Representative, Liz O'Neill, who took up this position late last year and we all look forward to working alongside Liz, as she fulfils this role.

Being within the Tuggeranong Community Health Centre, has enabled unique opportunities for our patients. We have been able to create partnerships with services at the Tuggeranong Community Health Centre that primarily optimise our patients wellbeing and in giving them back some of their valuable time.

Services include: Dental, Podiatry, Walk-in-Clinic, CALMs (after hours locum service), Pathology, Physiotherapy, Mental Health and Nutritional services.

With access to already familiar procedures and policies with ACT Health, and ongoing support with Diaverum, the Tuggeranong Clinic staff and myself will continue to strive for a positive dialysis experience with a focus on patient centred care.

Julie Green  
Clinic Manager  
Tuggeranong Dialysis Clinic  
Phone – 02 6207 0604

Official opening hours:  
Mon/Weds/Fri – 0700 to 2100h  
Tues/Thurs/Sat – 0700h to 1500h



## ORGAN DONATION IN AUSTRALIA -by Robert Little

On Wednesday 9 September at Royal Prince Alfred Hospital I was honoured to attend the *Leading Practice in Organ Donation: The Way Forward Symposium* held with Professor Raphael Matesanz Director of Spain's *Organización Nacional de Trasplantes*, (ONT) as guest speaker.

In 1985, I was the youngest on dialysis in the ACT. Organ failure dominated my life, but I had never really involved myself with the policy or politics of organ donation; I always assumed it was being dealt with as best as possible. Yet here I was at a Symposium on organ donation – how did I get here?

The resignation of David Koch 'on air' from the Organ and Tissue Authority's (OTA - also known as DonateLife) Advisory Committee caused me to look into the work of the OTA and organ donation in Australia. Koch resigned on the back of a decision of the Assistant Minister for Health, Senator Fiona Nash to look into the implementation of the organ-donation National Reform Program. What had happened to cause the Minister to ask for such a review?

**Australian's were promised that Australia would become a "world leader in organ donation for transplantation"**

On 2 July 2008 in a Joint Media Release between Prime Minister Rudd and Health Minister Roxon the following statement was made:

The Rudd Government today proposed a major new national reform package to establish Australia as a world leader in organ donation for transplantation.

Being a world leader would mean matching Spain at about 35 donors per million of population. Australia now languishes at just less than half that rate. We've dropped from 20th to 22nd in the last two years.

Clearly this is a long way from being a world leader as promised by the government. We're still behind countries such as Spain, Croatia, Malta, Belgium, Portugal, France, the US, Estonia, Austria and Slovenia to name just a few.

Despite claims that significant improvement has been achieved; we have only seen a modest increase in transplant activity over seven years (from 39.4 transplant recipients per million of population in December 2008 to 49.1 in September 2015). This gradual increase is far from what was committed to in 2008, and far from what has been achieved with the same plan in other countries.

What makes this tragic is there are people in the transplant "system" who are, seemingly, happy to accept Australia's low ranking. Shouldn't doctors, especially when there are systems in place in other countries outranking Australia so significantly, be outraged as they watch their patients die? The fact is most doctors, including those in the transplant "system" don't educate themselves about the Spanish system, about Australia's poor ranking or the changes that need to be

made to fix the system. More horribly, when faced with facts: statements by Professor Matesanz, and figures on organ donation many prefer to protect those who have brought us to where we are rather than demanding change. If Australia was in the top ten of countries one could accept such an approach. At 22<sup>nd</sup> such an approach is immoral.

This leaves an added bitter taste when \$250 million, a quarter of a billion dollars, has been spent on the program! If this was sport it would be unacceptable.

We know some of the things we need to do:

Accept that opt out is not the answer

Doctors dedicated to organ donation

Accept that opt out is not the answer

Identification of potential donors

Older/extended criteria donors

Accept that opt out is not the answer

Some people suggest that opt-out is the fix for the problems in Australia's organ donation system. My research suggests that this is not the case. The problems lie with hospital processes and practices. Professor Matesanz, has stated that "he does not think Spain's opt out organ donation system is a factor in that country's success, Australia has an opt in donation system. At the end both systems require the family to give consent."

Doctors dedicated to organ donation

Professor Matesanz has stated "Spain has more intensivists doctors in their hospitals which frees them up to spend more time with patients and with families of potential donors." This is the stated aim of DonateLife though it has not been carried out within any governance framework. I have heard stories of hospitals taking money for ICU organ procurement specialists and then giving that ICU doctor a full load of 'normal' ICU work preventing that Dr from carrying out their organ procurement role.

At the *Symposium*, Dr George Brieva Senior Staff Specialist, Donation Specialist Medical, Intensive Care Unit, John Hunter Hospital, specifically gave a presentation that untrained requestors were involved in the organ donation request and were failing. I pause here to note that he was open, articulate and honest about the problems he faced and the strategic problems he encountered in dealing with the OTA (ie. not enough trained requestors).

DonateLife recently looked into this and found:

A key finding of the evaluation was that there was a significant association between completion of the FDC training and a higher consent rate.

The presence of at least one FDC-trained professional in the FDC was associated with a higher consent rate: 69.3% compared with 45.2% where no FDC-trained professional was present.

I simply ask 'After 7 years how is it possible that untrained requestors are still doing a sizable portion of the requesting?'



## Identification of potential donors

At the *Symposium* Professor Matesanz stated "Spain's plan is to increase their donor rate from 35 to 40, the main focus is on identifying more potential donors." Let's look at that a bit more closely. While officials from Donate Life will tell you that all potential donors in Australian hospitals are being identified the Spanish are convinced that more donors could be found. Spain are not resting on their laurels as the highest donor rate country in the world. They passionately innovate and look to do better. Perhaps this is because the Spanish system is overseen by a doctor passionate about organ donation whilst the Australian one is run by a lawyer-bureaucrat passionate about covering up poor performance. The differences could not be starker.

## Older/extended criteria donors

Spain differs from Australia in that they have a strong focus on using older donors. They have deliberately pursued -

acceptance and matching of older and extended criteria donors with their transplant sector. Such an approach in Australia, DonateLife has said in correspondence with me "would require a significant shift in acceptance practices by transplant units." So, the cat is out of the bag. It's not about people 'having the conversation'; though that is important, it's not about anything in Australian culture; Australian's overwhelmingly would donate their organs, it's about the culture, governance, processes and practices in Australian hospitals. Dialysis patients in particular and those on transplant waiting lists in general should be more vocal. They deserve the best organ procurement system in the world. In addition doctors should be more vocal on behalf of their patients. As one example, the Australian Medical Association (AMA) should be as vocal about this issue as they were when the government mooted the GP fee. The Transplant Society of Australia and New Zealand (TSANZ) should also be vocal about this issue.

As patients we must listen to the experts at this and demand what our previous Prime Minister promised: a world leading organ donation system.

## ACT QUALITY IN HEALTHCARE AWARDS 2015

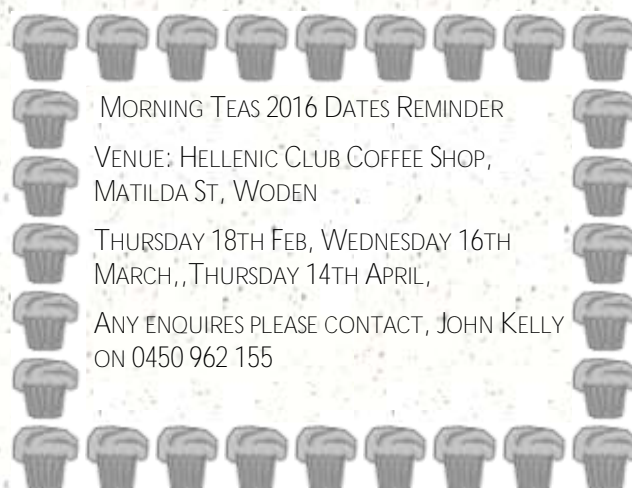


Congratulations to Renal Nutrition Project Team who were finalists in the 2015 ACT Quality in Healthcare Awards and attended an awards night at the Boat House Restaurant late last year.

The Renal Nutrition Project has worked to review and restructure nutrition services to ACT dialysis clients over the past 2 years. Nursing staff are now completing regular nutrition screening to identify symptoms associated with poor nutrition and trigger a referral to the dietitian. However the primary change has been commencing a regular dietitian service to ACT dialysis units to provide nutrition consultations during dialysis sessions. This new service has been successful as it promotes early intervention nutrition service, is more efficient for staff and more convenient for clients.

If you have any questions or concerns about your diet and

wish to speak with a dietitian please ask your dialysis nurse or nephrologist for a referral.



# INTRODUCING YOUR CONSUMER REPRESENTATIVES

*They Represent You on the  
Renal Advisory Meeting*



## CO-CHAIR

**JOHN SCOTT : 6255 1320**

"I am a Renal Transplant patient who has had Kidney disease since 1973. My kidney's finally failed in 1988. Over the years I have had Haemodialysis treatment both in-centre and at home as a home dialysis patient. I have been on the Renal Advisory Meeting from the beginning and am a former Senior Public Servant in the Commonwealth Health Department. I work privately in the area of risk identification and management"

## TUGGERANONG DIALYSIS CENTRE

**LIZ O'NEILL : 62949458**

I have been on dialysis for 3 years next may. I am married to Mark and we have 3 Daughters and 4 beautiful granddaughters, I can be contacted at home and/or via Marks mobile 0408713000. I look forward to forging new relationships and sharing experiences with one and all.

## GENERAL TEAM PASTORAL CARE

**MARY CORCKERON : 0427473290**

While clients receive professional care from nursing staff and those involved in their care from other disciplines, Spiritual Care is an essential aspect of caring for the whole person. I am a friend and spiritual companion which when summed up translates as one who LISTENS.

**BARRY COLE: 6288 2036**

I was a full time carer for about 10 to 12 years for my late wife. For the last 6 yrs of her life she was a PD patient. For the remainder of her life (July 2014) I used to set up the unit for night time use then clean out and empty out in the mornings 7 days a week. I am also part of the "Asprey" research group for older persons.

## CARERS ON THE RAM AND ALSO THE CANBERRA REGION KIDNEY SUPPORT

### GROUP

**JOHN KELLY-EMAIL : [CARERS@CRKSG.ORG.AU](mailto:CARERS@CRKSG.ORG.AU).**

"I am the carer of a renal transplant recipient. I am more than happy for people to contact me. Phone : 02 6231 4286. If I am not there please leave a message on how to contact you."

## YOU CAN BE ONE OF THE REP'S TOO

The renal advisory meeting objectives are to provide a forum where mutual information, advice and assistance can be provided to both the staff and patients at the renal unit at the TCH that relate to issues that may arise that may assist with:

- ♦ understanding the needs of all stakeholders in the renal services
- ♦ identifying initiatives that may improve patient care and well being
- ♦ provide a forum where open communication can be established and distributed through various networks
- ♦ improve the services that are provided by ensuring that they are consumer driven and focused on improving outcomes.

We currently need consumer representatives from **CCDC, 8A, PD and Home Therapies**.

Generally there is one meeting each month, held in the Renal Administration area and takes about 1 hour of your time.

If you would like to become involved please contact this office and further information will be provided.

Email: [shradha.waddepalli@act.gov.au](mailto:shradha.waddepalli@act.gov.au)