

Board members 2006-07

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Strategies

The strategies we are pursuing are:

- a parallel process of communicating the project issues and development between bush and town, family and home community
- the development of appropriate resources, including Yanangu themselves, to inform patients and families about treatment options
- a program which pays for six return flights per year per patient to their home community
- improving the living experiences of those currently on dialysis
- working with local and regional services to identify appropriate treatment options, including self-care dialysis on remote communities
- working with people about to enter dialysis
- incorporation

Roster:

Next week Robin Cromer and Bernadette Capello will be producing the Raven, whilst Des Pain will be on leave. Please address all material for the Raven to them, until further notice.

	THIS WEEK 1st Nov	NEXT WEEK 8th Nov
Program	Jacki Couchi Coping with the stresses of retirement	TBA
Introduction	Des Pain	Bernadette Capello
Appreciation	Bruce Wyatt	Gary Scott
Fellowship	Neale Emanuel Tom Davies	Robin Cromer Piers Booth
Raven Recorder	Val Bland	Robin Cromer
Birthdays	Shirley Evans 4th Nov	Ken Goard 12th Nov
Anniversaries	nil	nil
Trash &	5th Nov Piers Booth-Ajit Banerjee	12th Nov David fox-Gary Scott
Treasure	19th Nov Des Henderson Kelly-Val Bland	26th Nov Bruce Wyatt-Ros Osbourne

Tonight:

Jacki Cauchi

on

Coping with the stresses of retirement!

Jacki was born in Wales, moved to Sydney with her parents at the age of 11, attended Fort Street Girls High school before marrying John and moving to Canberra. She worked for the Taxation Office whilst studying for a BA Accounting and producing 2 children, Paul (27) and Steven (24). Jacki moved into Public Practice and was employed in Canberra and Coffs Harbour before becoming a partner in an accounting firm in Canberra. Over the next 15 years Jacki served on numerous committees including various CPA committees and Taxation Office Committees as well as acting as Treasurer, of a university residential college, of District Rotary and of the Canberra Woden Rotary Club. Jacki made a decision in 2003 that it was time to enjoy life a bit more and thus decided to retire from full time accounting life. The last 2 years have been spent seeing some of her backyard.

Last Week:

Last Friday at the front of Parliament House at 4pm Senator Gary Humphries, President Ray and members of the Rotary Clubs of Canberra Weston Creek and Canberra Woden welcomed 23 elite athletes to Canberra. The ride was being conducted by the Sunrise Foundation in association with ARHRF. It was led by Wayne Schwass. Our intrepid Club cyclists John Widdup and Noel Hart led the riders into Canberra.



A special welcome to PDG John Lawrence who has recently been appointed Director of the Board of RI (2008-2010), to take effect on 1 July 2007. A presentation of her dinner badge to Judy Skelton was made with the Classification of *Property Investment*. Please note in the Raven the formal notice of the Club's AGM on Wednesday 29th November. Members are urged to indicate to President-Elect Tom Davies their possible availability for Board Membership for next Rotary year.

*David Fox proposed the concept of a **Major National Project** for the Club to help the local Aboriginal people living around Kintor (see Map p4) help themselves. The people have already taken a stand to overcome kidney disease and the abuse of alcohol. They raised around 1M dollars through auctioning paintings at Sutherbys in London. They used the funds to buy 5 kidney dialyses machines and 2 toyota troop carriers to transport their people to a new building to have treatment. They have one paid staff who helps setting the patients up on the machines. The aim of OUR project would be to assist the locals to raise funds and to continue to help them selves without bureaucratic interference. [SEE ARTICLE page 3]*

The concept is to have one Rotary Club in each State support the project and to use it as a local FAIM project in Australia. Our club was highly supportive, and David is continuing with setting up the project so watch this space!

Shukry Sahhar was given a rousing fine session by Rex Hunt for turning 60 this week end. John and Janet Lawrence made up at the club on their way to the District Conference. It was good to catch up with the Lawrences and to congratulate them on John's election to the Rotary Board for 2008 -2010

Guest Speaker Tom was stationed at 800 Signal Squadron in Port Moresby for a year as part of his training as an Officer at RMC Duntroon. Tom Davies intrigued the club with his talk on one day in the highlands of New Guinea. Tom showed a series of slides (yes those things we used to take before the age of digital cameras) to show how time has changed in the highlands. The area used to be an Australian Territory and Australian servicemen were used to train and lead the local PIR (Papuan Infantry Regiment). They wore green uniforms with short sleeve shirts, shorts, long socks and boots with gators, and berets. They were very smart and orderly.

The hill tribes would get together once a year alternating between Mt Hagan and Goroka. The festival of the feathers gave the men a chance to

This small group all use peritoneal dialysis (PD, or "the bag"). No-one from the project region has ever returned home to live on dialysis. At the start of the project in April 2001, fourteen people from the Western Desert were on haemodialysis in Alice Springs, including members of three generations of one family. One year later, six of those fourteen people have passed away.

Most of those on dialysis in Alice Springs survive less than five years, compared to eight nationally. In the mid-1990's, people from the project region survived about 2 years! Discussions in one large primary health care service suggested that up to 25% chose palliation rather than dialysis away from their country.

A World-Wide Story

Many Yanangu over 40 were born in the bush, and came with their families to government settlements between the 1960's to the 1980's (both voluntarily and involuntarily). They share with all other Aboriginal and Torres Strait Islander people the exposure to the spasms of change that have been directed by non-indigenous powers.

There is virtually no private economic activity apart from fine-art. Mineral royalties and welfare payments provide most of their income, placing them in the lowest 10% income nationally. Unemployment rates are above 90% (disguised by work-for-the dole schemes) and living costs are high - fuel is \$1.35/L, a small tin of Milo \$5 and bread more than \$3.

This picture of disease accompanying rapid lifestyle change, poverty and disadvantage is shared by indigenous populations world-wide.

Project Strategies

Our central strategy rests on Mr. Zimran's philosophy that underlying control must rest in the hands of the people affected. To this end the Kidney Committee - both as informed individuals and a regional body - binds workers, members, communities and patients. There is a partnership formed when sitting down to understand the many issues surrounding dialysis from the mainstream perspectives of community, patient and provider. Problems, reflection and action require sharing between all stakeholders - both out bush and in town.

and they feel they are weak because they have taken away the power in the community. That is the whole issue about community control under Aboriginal law”.

It is also not surprising that the call for Aboriginal self-government in Central Australia is being led by the remote regions. Mr. Zimran tried to make those working closely with him understand the significance of Yanangu Law and take the message to other Australians. He was involved in many projects directed at the betterment of his people and developing an understanding between us all.

In 1998 Mr. Zimran became the chairperson and guiding hand for the Combined Aboriginal Nations of Central Australia (CANCA), a body committed to the recognition of Aboriginal law and self-government in Central Australia.

The vision he continually expressed was that of having those elements which define Yanangu being within their own control.

Kidney Services in Central Australia

Most regional kidney-related services are provided from Alice Springs. The town has 27,000 people, of whom 20% are Aboriginal and it lies exclusively in Arrente country. knangu from the Pitjantjatjara lands in South Australia also look to the Alice for most services, as do those from the eastern Ngaanyatjarra lands in Western Australia. Currently (2002) there are about 80 people on haemodialysis in the Alice Springs renal unit which has enough space for 102.

Aboriginal people in the surrounding remote communities suffer end-stage renal disease about 30 times the national average. Individuals usually have type 11 sugar diabetes, high blood pressure and heart disease as well.

While Aboriginal people are only a quarter of the NT population, they make up about 90% of the people on dialysis. Most of these are women, who begin dialysis ten years earlier than others in Australia but enter the hospital system later, usually as a critically-ill patient. Though most people come from remote areas, only about 10% ever return home on dialysis compared to 38% of people nationally.

dress in their best regalia and to show off to the other tribes. Prior to this the natives would gather to settle old scores. It was fascinating to see the different feathers and the attire worn by the different tribes. Whilst the gathering started off very friendly, the taunts and old scores would surface and spears would be go from the vertical to the horizontal as the day progressed.

The local police would try and keep order and the axe handles they carried were useful reminders of how persuasive they could be.

Tom showed the start of the Kokoda trail and how quickly it changed into a thick dark jungle and the old memorials to the fuzzy wazzy angels and to the fallen soldiers. Tom did walk the trail and it took him 8 gruelling days.

If you weren't there you missed a good night. Thanks Tom.

Thanks to Recorder Shukry Sahhar

Attendance: Hon Member: Frank Macklin. Visiting Roatrians: John and Janet Lawrence. Guest: Michael Henderson Kelly. Make-up: Peter Evans. Number of Members present: 22. Percentage: 78.57%

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## **Western Desert Dialysis Appeal**

‘Your place or mine’ - dialysis in Central Australia

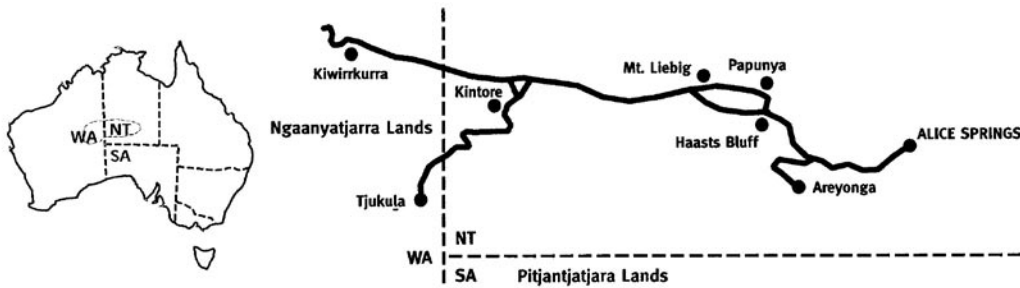
### **Introduction**

This story is about the people of the Western Desert of Central Australia - Yanangu. It is about art, money, the devastation of kidney disease in our remote communities and in particular about one man's vision for a future. Kumantjayi Zimran Tjampitjinpa was a remarkable Pintupi man who passed away in December 2000, having been a patient in the Alice Springs renal unit for almost 4 years. His vision and efforts laid the foundation for the Western Desert Dialysis Appeal to work to bring back people on dialysis to their own communities on treatment.

The Western Desert Dialysis Appeal (WDDA) is a non-government organisation entirely funded from the sale at auction of indigenous artworks from communities in the Western Desert.

### **The Region**

Most of the 1200 Aboriginal people living in the remote, arid area west of Alice Springs live on parts of their traditional country in extended family outstations or on larger communities of a few hundred like Kiwirrkurra, 700 km west of



Alice, across the WA border. Pintupi, Luritja, Pitjantjatjara, Ngaanyatjarra and some Walpiri, Western Arrente and English are spoken in this area.

The people within this region refer to themselves as Yanangu.

The WDDA Kidney Committee has about fifteen Yanangu members who recognise their responsibilities to organisational membership through their cultural obligations of kinship, traditional country and ‘tjukurrpa’ (sometimes referred to as ‘dreaming’).

### Community Life Disrupted

In the late 1990’s, many Western Desert people talked about the alarming number of their people needing kidney dialysis and the way treatment was being delivered. They talked about the disruption and loss to family and community life when patients and their families have to shift to the Alice Springs dialysis unit. Once in this regional unit, they live, and then inevitably die, so far away - haemodialysing “on the machine”.

Senior men and women at the peak of their community influence, become chronically unwell and shift with their families for dialysis to Alice Springs - someone else’s country. They are then asked to guarantee regular attendance at a clinical institution, almost another world, where they sense minimal respect and have very little control of their lives.

This was the experience and reality of Mr. Zimran, the man who brought this Western Desert Dialysis Appeal to a reality and whose legacy we are trying to fulfil.

### Astonishing Fundraising

In early 2000, an informal alliance of Aboriginal community representatives, local ALP politicians, art collectors and dealers planned an auction of donated artwork and four specially-commissioned paintings by men and women from Kiwirrkurra (WA) and Watungurru (Kintore) in the NT.

By the end of the year over \$1M had been raised, an astonishing sum, principally through a Sotheby’s auction in Sydney. This money now finances the Western Desert Dialysis Appeal project, which aims to bring back individuals and their families from Alice Springs to dialyse on their home communities.

Neither the NT nor Federal governments has offered to match this money on a dollar for dollar or any other basis.

### The Kiwirrkurra Men’s Painting

Yanangu do not see their paintings as inanimate objects but as representations of life at various depths. The painting shown here is known as the Kiwirrkurra Men’s Painting, one of the four specially-commissioned works. This painting shows Yanangu obligations of ngurra (traditional country), walytja (kinship) and tjukurrpa (dreaming).

These three elements are all interrelated and through many complex processes of learning and understanding, form the basis of being Yanangu, a process commonly referred to as ‘The Law’. This is the way that Mr. Zimran understood who he was and defined himself. One artist explained that the stories accompanying the paintings when sold were only the surface. They are like an iceberg which displays only one tenth of its bulk above the sea level. Given the difficulty that many have in comprehending even the surface of a Yanangu world, it is not surprising that policies and programs directed at Yanangu fail to achieve their stated aims.

### Community Power

“The law is like a human being, it works with Aboriginal people-Anangu. Anangu and the law is together, if that law is weakened, people get weakened