

Friends of the Western Desert Dialysis Appeal

Newsletter 2, Summer 2001

Dear Friends and Supporters,

This is the second newsletter of the Appeal aiming to keep you abreast of developments, as the project continues the work to bring people on dialysis in Alice Springs, back to their communities on treatment.

The Kidney Committee

On November 6-8th 2001, the first full meeting of the Kidney Committee took place at Hamilton Downs, an outstation complex 75km west of Alice Springs. The logistics of bringing people from so many far-flung communities are a good example of the complexities facing the project. With Kiwirrkurra still cut-off by floods, some drove almost 2 days from Mullen (Lake Gregory) to attend. Members now include Bobby West Tjupurrula, Donald Mathews Tjapanangka, Lorna Graham Napangati, Lloyd Shepherd Tjakamarra (Kiwirrkurra), Marlene Nampitjinpa, L. Corby Tjapaltjarri, Victor Robinson Tjungurrayi (Kintore), Yuyuya Nampitjinpa, Bundy Rowe Tjupurrula (Mt. Liebig), Jeffrey Zimran Tjangala, Alice Nampitjinpa (Haasts Bluff). The broadening of membership now includes representatives of almost all the larger communities in the Western Desert region.



Kidney Committee, Back row: Donald Mathews, Bundy Rowe, Jeff Hulcombe. Front row: L. Corby, P. Rivalland, Jeffrey Zimran (kneeling), Marlene, Yuyuya and Alice Nampitjinpa.

The meeting gave us all an opportunity to discuss issues and to come to an agreement for future developments.

Building A Remote Renal Unit- Too Difficult

Probably the biggest hope for everyone concerned in the Appeal, was that some sort of renal unit could be constructed at Kintore. Costings of a variety of scenarios were carried out by Gill Gorham of the Darwin Renal Unit at the request of the Appeal. She has been responsible for setting up the Tiwi Unit (Bathurst Island) and has considerable remote experience. In addition, work done by Katherine Brown for the Pintupi Homelands Health Service on the assessment of the Kintore water supply was utilised. Summarising all this work lead the Manager, and subsequently the Kidney Committee to realise that a renal unit in Kintore for the 13 people currently on dialysis in Alice Springs was not possible. Major reasons were:

- there was insufficient water for the unit and the families of people relocating
- a new power generation and water filtration unit would need to be built
- major road and airstrip upgrades plus maintenance were required

- the expense of the building (\$1.5 million), staffing (\$300,000/yr) and their accommodation, employment difficulties, dialysis machines and maintenance. Neither Territory and Commonwealth were willing to contribute to capital infrastructure.

Don't Despair - "Self-care"

Not having a unit doesn't mean people can't go home. In the last newsletter the possibilities for haemodialysis ("the machine") and peritoneal dialysis ("the bag") being carried out at home were outlined. This is now the focus the Kidney Committee has said the Appeal should adopt, making the point that they were unaware that these options are available nationally for all Australians. Transplantation should still be considered a possibility. Provision of self-care renal services are the responsibility of the state or territory. Currently in WA, remote communities are provided with the options of both peritoneal and haemodialysis. In Alice Springs, only peritoneal dialysis is supported, and to a much lesser degree than elsewhere. No-one from the Western Desert has ever returned home on self-care. Here lies the crux, the Appeal Project is advocating that governments take on their full responsibilities and put in place the training and support which is required for such a self-care service. The Project will be responsible in working with these mainstream services and supporting Aboriginal people to utilise them in the best way they see fit. This responsibility requires a local and a regional community approach.

Over the past few months, negotiations between the Project, Commonwealth and the local health service at Kintore have been taking place to ensure that a space was set-aside for self-care in the

plans for the new clinic. These have been completed, and that a room will be constructed with suitable essential service infrastructure such that a haemodialysis machine could be set-up, should there be someone suitable. Peritoneal dialysis could also be maintained in the area. It's the intention to provide appropriate details to other health service organisations such that similar areas could be constructed in remote area clinics.

Working In Town, Working Out Bush

To get information to individuals in the renal unit, their families in town and out bush requires someone with unique skills. The Kidney Committee decided to ask Jeff Hulcombe to work for them, initially until the next Committee meeting in early April 2002, as a part-time worker, similar to the Manager's position. Jeff has immense local experience, is a Pintupi-speaker with training in education and community development. He's well-known to people and was a unanimous choice. As well as carrying on the process of sharing information in town and out bush, Jeff will be working with the staff responsible for training, supporting individuals to go home.

Kidney Committee And The Big Picture

Aboriginal people living in the geographical area within the Appeal focus, are subject to a complex array of health and funding organisations. The Kidney Committee sees the Appeal funds as being utilised for 'family' communities, (Kiwirrkurra, Kintore, Mt. Liebig, Papunya, Haasts Bluff), the latter four known as the 'Wanka Walytja' group:



Western Desert Communities

To achieve this they have employed a manager (Paul Rivalland), a medical practitioner whose background is in remote health. To assist the project, he is actually employed by the Centre for Remote Health (see <http://crh.flinders.edu.au>) in Alice Springs, a joint venture of the Flinders and Northern Territory Universities. As well as providing practical support, John Wakerman (Assoc. Professor and Director, CRH) provides supervisory support to the manager and project development.

Remote health services are funded by the Commonwealth (Aboriginal Medical Services (AMS) including Ngaanyatjarra Health in Kiwirrkurra and the Goldfields region; Pintupi Homelands Health Service in Kintore), and the Territory Health Service (THS), with the regional renal units in Perth, Darwin and Adelaide having roles in individual patient care along with the satellite units in Alice Springs and Kalgoorlie. Broadly speaking, renal services are the responsibility of the state or territory, but the Commonwealth has been previously involved with one-off capital payments, and is currently pursuing a process of regionalising and increasing primary health care funding. The Appeal project has been liaising throughout, across borders and at the local, regional, state and Commonwealth levels with individual and representative

bodies including Aboriginal organisations to identify support and barriers. This is a slow, continuous process, but one that will help support long-term outcomes.

The Next Phase

As foreshadowed in the previous newsletter, a small video has been made by the project about self-care home haemodialysis, showing people doing this in Darwin and the Kimberley. At the Hamilton Downs meeting, the Kidney Committee resolved to go and see this first hand, in order to talk more knowledgeably to their home communities. So in early April 2002, after the Wet season, about 15 members hope to travel by road towards Bityadanga (La Grange) and visit remote communities on the way where people are self-care dialysing. A full Committee meeting will be held at the end, where Jeff will present the results of his 5 months work and discussions will take us on to the next step. The Manager will also be presenting options for a restructuring of the Appeal Fund, ensuring continuing accountability, but a more independent body responsive to Committee direction. Parallel to the 'grass-roots' work in Alice, the project is supporting the developing regional push for self-care and a robust approach to renal disease in the Centre.

Further donations welcome!

The bulk of the money raised by the Appeal is invested and raising interest. A smaller current account is used for the manager and project worker salaries, 'Return to Country' program and running costs.

Further donations are welcomed, they're tax deductible and greatly appreciated. If you wish to contribute to this important project, please forward monies to: Western Desert Dialysis Appeal, c/- P O Box 562, Howard Springs, NT 0835

If you want to make contact about issues or donations, please call:
Paul Rivalland
ph: 08-8983 3367 or email:
kidney @ octa4.net.au