

Friends of the Western Desert Dialysis Appeal

Newsletter 1, Winter 2001

Dear Friends and Supporters,

It may seem a while since you heard any news of the Appeal, so this newsletter aims to bring you up to date with developments. There will be future editions as we move along the path aiming to get people from the Western Desert currently on haemodialysis in Alice Springs, back home living with their families. We shouldn't underestimate the time this will take, and one of the ideas behind the newsletter is to take the opportunity to inform every one of the issues.

The Kidney Committee

At the end of last year, with the successful completion of the art auction and sale, a committee of eight people from the communities of Kintore and Kiwirrkurra became the representative body giving instruction to the Appeal project. From Kintore: L. Corby Tjapaltjarri (President), Yuyuya Nampitjinpa (Vice-President), Victor Robinson Tjungarrayi and Marlene Spencer Ross Nampitjinpa. From Kiwirrkurra: Bobby West Tjupurrula, Lorna Graham, Lloyd Shepherd and Donald Mathews.

We should pay our respects to the life and hard work done by S. Zimran Tjampitjinpa, who passed away not long after the auction.

Manager

One of the decisions in April by the Committee was to appoint a part-time manager - Paul Rivalland. Paul is a medical practitioner, currently based south of Darwin, who has extensive bush experience, including working in both communities over a period of years. He will visit them every 2-3 months. The appointment has been made through the Centre for Remote Health, a collaborative research centre based in Alice Springs, who are offering project support.

The Funds

An audit was completed at the end of last month. The documentation hasn't yet been sighted, but discussions with the accountants show no problems. A short-term investment account holds the bulk of the funds.

Return to Country

One of the principal concerns to the communities was the difficulties people receiving treatment in Alice Springs had in maintaining family and cultural ties with their kinfolk in the remote west, without compromising their dialysis treatments. The 'Return to Country' program enables patients to visit their homes six times a year. With support from Jonathan Pilbrow,

the renal unit social worker, return trips using appropriate transport can be organised. It is available to people from all the Western Desert communities as the Committee sees fit. Budget projections suggest this will cost \$18,000 p.a.

Getting people home

"When are you getting the machines?" is the common question and if only the answer was as brief. People whose kidney function is so bad that it requires technological support can choose a variety of treatments: peritoneal dialysis (tipping bags of fluid in and out of a tube in the abdomen four times daily or at night), haemodialysis (using a specially prepared forearm blood vessel as an access point to connect up to a machine three times a week), transplantation and deciding not to have treatment at all. In the recent past the latter has been taken up with depressing frequency by people, particularly the elderly.

All of these modalities have pros and cons and are utilised variably by the renal units across the country. In Alice Springs the majority of Aboriginal patients (including the fourteen from the project area) are treated by haemodialysis, unable to go home. In other states, and more recently in Darwin, there is a growing trend to invest in teaching people how to use their machines at home. This is the cheapest option, reducing pressure on renal units and more importantly giving control back to people's lives.

Western Australia in particular supports several Aboriginal people currently in remote areas on haemodialysis, using the local clinic as a secure, safe and private location for dialysis.

Whilst the project will be costing all types of treatment scenarios, currently the most cost-effective and sustainable broad program would be 'self care' and what is required to support patients and their families to achieve this.

Getting there

To ensure that the community be as fully informed as possible of the options available, a series of Committee visits to Aboriginal people using different modes of treatment is being planned.

The emphasis will be on 'self care', exploring what individuals and their families can do themselves to get home. Important meetings with the patients themselves in Alice Springs can then be held, with the Committee telling of their experiences. We hope to make an information video as we go along.

Both communities have clinics under reconstruction. The one at Kintore is being replaced and Kiwirrkurra, still flooded out, may be relocated later in the year. This provides the project with the opportunity to ensure that the relevant essential services (power, water, sewage and communication) are laid down appropriately to allow 'self care' haemodialysis should it proceed.

At the same time discussions are proceeding at the local, regional and state level with the relevant health services which straddle the borders of the N.T. (for Kintore) and W.A. (for Kiwirrkurra). Though individuals are in Alice Springs, cross-border care is a big issue.

We'd like to thank all those who have given so much time and effort to get the Appeal up and running over the last couple of years. As the project evolves, we will try to keep you as involved as possible.

If you want to make contact about issues or donations, please call:

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