

Friends of the Western Desert Dialysis Appeal

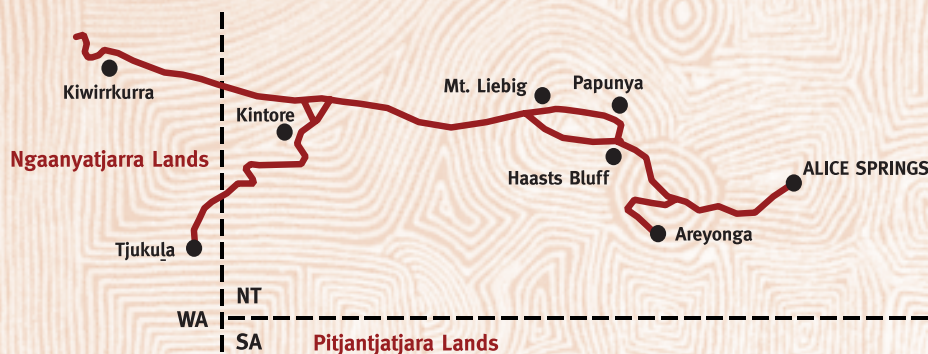
Newsletter 3, Winter 2002

Dear Friends and Supporters,

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

Committee Visits People on Self-care Dialysis

At the last full meeting of the Kidney Committee in Hamilton Downs (11/01), members requested that they be able to learn more about people doing dialysis for themselves - self-care dialysis treatment.



Communities in the WDDA area

The Kimberley (WA) has the most active program supporting dialysis in remote Aboriginal communities, so at the beginning of June/02, the Committee and support workers traveled from their home communities up through the Tanami Desert in 2 Toyotas to visit. Over 10 days we covered two and a half thousand kilometers, stopping in the communities of Hall's Creek, Bidadanga and Broome.



Self care in communities — doing PD in the local clinics



During the trip we met people who were doing their own dialysis, either in their own homes or in rooms in the local clinic. We managed to see both peritoneal and haemodialysis being carried out.

During the trip, we held meetings to plan and develop strategies for the future of the Appeal project, which are discussed below.

Western Desert Ngurra Walytja Tjutaku Aboriginal Corporation

The Kidney Committee decided to undertake a process of incorporation under the Commonwealth Aboriginal Councils and Associations Act. Legal advice suggested that this would allow us to seek further funds from governments or appeals; own assets and facilitate an accounting structure responsive to our needs; clarify lines of responsibility and affirm the decision-making role of the Kidney Committee.

Though a simple process in theory, in practice it will take several months of discussions to fully inform participants. All information is translated and made available on audiocassette for wider dissemination amongst community members. We hope that incorporation will be complete by September.



WDDA - Kidney Committee

Top left: M. Nampitjinpa; D. Matthews

Top right: L. Corby; J. Zimran

Bottom left to right: J. Hulcombe, B. Rowe, A. Nampitjinpa, Y. Nampitjinpa, L. Graham, B. West, P. Rivalland, A. Bates and C. Tjapaltjarri.

Self-care Developments

After seeing what was possible for people on dialysis at home, the Kidney Committee requested that a program for self-care training be costed. Previous newsletters have outlined the contrast between centre-based and self-care dialysis, especially the positive cost and quality of life benefits of the latter.

In addition, members requested that we consider a 'reverse-respite' program. It was clear that there were some people on dialysis in Alice Springs who would be unable to take advantage of self-care training. However the Kidney Committee felt strongly that these people should not be denied the opportunity ever to return home. Thus a program of short, 3-week visits to Kintore, supported by a specialist nurse would be developed, giving patients respite from the renal unit in Alice Springs. This is what we've called 'reverse-respite'. Costings will be presented to the next meeting in Alice Springs in September. The new clinic in Kintore will hopefully be finished by the end of the year, and has a space within which the essential services for a single-patient haemodialysis system have been placed. It is the intention of the Ngaanyatjarra Health service to place a similar space inside the reconstructed clinic in Kiwirrkurra later this year. Thus we should have two identical locations either side of the border ready for service delivery.

Next meeting of the Kidney Committee

This next meeting will be exciting as it will be the first decent opportunity Committee

members have had to formally present the project's progress to families on dialysis. We intend to provide a forum where the incorporation, costings and issues can be discussed to enable a cohesive plan involving those in town and out bush to progress.

To prepare for this, a number of issues have been addressed which will be briefly outlined:

•Workforce

Paul Rivalland (manager) has changed from part- to full-time work.

Jeff Hulcombe has had to stop work, though remains intimately involved. Joy Wurst has started working part-time to support patients in the unit around every day 'quality-of-life' issues' eg. hunting, painting, communication.

•Local advocacy

The Kidney Committee and the work by Jeff have highlighted the need to support advocacy for those on dialysis. We are still trying to develop adequate translation and interpretation services for issues confronting patients and families. We have paid to provide interpreting during patient consultations with the visiting nephrologist. We are starting work on a Pintupi video about peritoneal dialysis, similar to our other one on haemodialysis.

•Regional advocacy

We continue to work on the development of a strategic plan for renal health in the region under the auspices of the NT Aboriginal Health Forum, the peak health planning body. We have pushed for such a plan to acknowledge the needs for the WA/SA cross-border issues to be addressed. In addition we are scrutinising work to institute national guidelines and treatment protocols within the Alice Springs renal unit.

Momentum of The Project

The breadth of the project across national, regional and local issues is considerable, and it's possible to lose focus – to get people home on dialysis treatment. Jeff and Paul were invited to give a presentation to the WONCA conference in Alice Springs recently, an international gathering concerning remote indigenous health-care. We spoke of the work and experiences of Kumantjayi Zimran Tjampitjinpa, the prime mover behind the Appeal, who passed away on dialysis in 2000. In particular we described his emphasis that Aboriginal people should have the power to develop their own destiny, and the influence this has upon the development of the Appeal project.

"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 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".

Kumantjayi Zimran, 1997

This presentation is available electronically as a pdf file.

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

Paul Rivalland
ph: 08-8983 3367 or email
kidney@octa4.net.au