NPY Women's Council:
Advocacy: End Stage Renal Disease

"The incidence rate of end stage renal disease among the Indigenous population has increased by 185% between 1991 and 2006…Indigenous Australians were 26 times as likely to register for treatment of ESRD as other Australians in remote areas, 18 times as likely in outer regional areas and 12 times as likely in very remote areas[1]."

The Issue

In Central Australia there are close to 200 Aboriginal people with end stage renal disease (ESRD) on regular dialysis, with around 40 of these from the NPY region[2]. The wider Central region has hundreds more in 'pre-dialysis' stage, and the Western Desert sector has the highest rate of ESRD in Australia. Alice Springs has been the main location for end stage treatment. A number of NPY members, their husbands or other family members are, or have been, renal dialysis patients. Several members who must live in Alice Springs because of their own or others' need for dialysis are involved with the NPYWC Tjanpi Desert Weavers arts social enterprise (see Fact sheet 12.)

In January 2009 the NT Government decided to stop accepting new end-stage renal failure patients from SA and WA for treatment in Alice Springs, citing an increase in numbers and insufficient facilities.

NPYWC had previously advocated for ESRD sufferers mainly in relation to: hardship involved in the move from communities to Alice Springs for dialysis; the need for additional secure, properly managed housing; local transport; budget issues; and the need for funding assistance for short trips home to allow for continuing with community of origin and family.

Prevalence

In 1998 ESRD was being described as an *epidemic* that would need greatly increased resources; at that stage the incidence in Aboriginal people was doubling every four years[3]. Causal contributors may include:

- obesity; raised blood pressure (hypertension); high blood triglycerides; low levels of 'good' cholesterol; higher than normal blood glucose levels ('Syndrome X' factors);
- repeated bacterial infections of ears, nose, chest, skin, gut and genitourinary systems, and endemic intestinal parasites; and
- social factors such as: loss of employment when equal pay was introduced, access to alcohol, increased welfare benefits, and availability of a high-fat, high-carbohydrate diet[4].

The reduction in infant mortality rates and improved nutrition and infectious disease management in Aboriginal children from the late 1950s to the late 1970s is believed, ironically, to have led to the greater survival of infants who then became part a cohort of obese adults with hypertension and diabetes[5]. Aboriginal dialysis patients usually live for around five years once they go on 'the machine.' Overall mortality rates from chronic kidney disease (CKD) in Aboriginal communities are up to ten times higher than for the general population[6].

Action

NPYWC objected to the rejection of interstate patients by NT Health, and urged the respective Ministers to sort out the problem. It argued that having to move even further away was 'doubly cruel' and 'likely to make end stage kidney failure even more distressing and unsettling[7]. In October

2009 the SA Health Minister John Hill advised NPYWC that a new Alice Springs dialysis unit, due to be completed in early 2010[8], would give renal patients from the Anangu Pitjantjatjara Yankunytjatjara (APY) Lands, in the NPY region, the option 'if clinically appropriate' of treatment in either an SA facility or in Alice Springs. This proved to be somewhat less than accurate. Confusing and confused responses continued to come from Health Ministers, as NPYWC would later put to federal Health Minister Nicola Roxon[9] and to a Senate Inquiry submission in April 2010[10].

By early 2010, NPYWC had become increasingly frustrated with the numerous unclear government responses. ESRD patients from NPY communities in SA and WA were (and still are) living, often miserably, in Adelaide, Kalgoorlie and Perth, or facing that prospect. One of NPYWC's elderly former Directors and staff members from the APY Lands looked likely to be the next. In February the organisation and supporters commenced a media and political lobbying campaign, focusing on the unfairness of the incurably ill and sometimes elderly having to move not only not hundreds of kms. to Alice Springs, but in some cases more than 1500 kms. to Perth or Adelaide for treatment, because governments could not plan co-operatively for regional services[11].

In mid-March the SA Health Minister announced that the three governments had agreed that there would be eight permanent places in Alice Springs for patients from SA and six for those from WA[12]. As the number of SA and WA patients already receiving treatment in Alice Springs already well exceeded these limits[13], this meant that new patients over and above these low allocations would not be able to take the place of those who died (or in the unusual event of a transplant.)

NPYWC and others who had opposed the exclusion eventually persuaded the Australian Government to investigate further. In July it announced that it would contract a *Study on service planning for renal dialysis services in remote and very remote areas*[14] to recommend clinical service delivery models and 'care pathways' to meet current and projected needs for Aboriginal patients from remote Central Australian communities who need dialysis.

NPYWC is advocating for governments to allow options to remote renal patients, including, where possible, treatment closer to home and access to mobile dialysis units, or where this cannot be done, in the regional centre of Alice Springs. WA and SA residents of the Central region, as well as NT residents, should be able to opt for Alice Springs in order to be closer to their families and home communities.

References

1 *Aboriginal and Torres Strait Islander health performance framework 2008 report*, Australian Institute of Health and Welfare, 2008. Online at: www.aihw.gov.au/publications/ihw/aatsihpf08r-da/aatsihpf08r-da-sum.html
2 Mid–2010.
3 *An epidemic of renal failure among Australian Aboriginals*, Spencer J., Silva D T., Snelling P. and Hoy W., Medical Journal of Australia, 168, 1998. Online at: http://mja.com.au/public/issues/jun1/spencer/spencer.html#refbody11
4 *Kidney disease in Australian Aboriginals: time for decisive action. Can governments and healthcare services in Northern and Central Australia afford not to get organised?* Thomas A B., Department of Nephrology, Royal Perth Hospital, Medical Journal of Australia, 168, 1998. Online at: www.mja.com.au/public/issues/jun1/thomas/thomas.html
5 See Ref. 4 above.
6 *Fast Facts on CKD in Australia*, Kidney Health Australia. Online at: www.kidney.org.au/KidneyDisease/FastFactsonCKDinAustralia/tabid/589/Default.aspx
7 NPYWC correspondence to the NT, SA and WA Health Ministers, August 2009.
8 Eventually opened in mid-2010
9 NPYWC correspondence to Minister Roxon, March 2009, seeking her urgent intervention in the matter, arguing that [rejected renal patients] 'are nothing less than Australians in exile, living far from home while the respective Health Ministers obfuscate and pass the buck.'
10 See: www.aph.gov.au/Senate/committee/indig_ctte/submissions/sub115.pdf
11 See for example ABC Stateline: www.abc.net.au/news/video/2010/03/19/2851258.htm; ABC news: www.abc.net.au/news/stories/2010/03/11/2842665.htm?site=idx-n t or www.abc.net.au/news/stories/2010/07/13/2952357.htm or the NPYWC website at: www.npywc.org.au/html/publications.html
12 Limited to residents of Ngaanyatjarra communities to the east of Warburton. The rest would have to go to Kalgoorlie or Perth.
13 Around a dozen from WA and around 16 from SA in mid-2010.
14 See media release and Terms of Reference at: www.health.gov.au/internet/ministers/publishing.nsf/Content/B6EEB61F5D4608A2CA25776500234CAC/$File/ws070.pdf

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Background artwork by Rene Kulitja. *'Three sides of NPY'* 2009.