



29 January 2018

PBAC Secretariat MDP 952
Department of Health and Ageing
GPO Box 9848
Canberra ACT 2601

Re: Listing on PBS for Jinarc (tolvaptan)

Polycystic Kidney Disease (PKD) is the most common genetic kidney disease and is the single largest cause of Chronic Kidney Disease (CKD) needing Renal Replacement Therapy (RRT). It is characterised by the proliferation of fluid-filled sacs in the kidney progressively impinging on kidney function. Among the most serious physical side effects are hypertension, which can lead to heart disease and aneurysms, pain and severe discomfort.

Autosomal Dominant PKD (ADPKD) affects at least 1-in-1000 irrespective of gender, race or ethnicity. What distinguishes ADPKD from broader CKD is that a person with ADPKD has a 1-in-2 chance of having a child with ADPKD and does not skip a generation. This inevitability causes emotional stress as a person with a confirmed diagnosis of the disease looks at their parent experiencing declining kidney function with repudiation while at the same they view their children with guilt.

Jinarc (tolvaptan) is the first drug to offer the possibility of slowing the rate of decline in kidney function thereby delaying the need for RRT, which in turn removes some pressure from the provision of dialysis and kidney transplants.

In conclusion, PKD Foundation of Australia and Kidney Health Australia strongly urges PBAC to approve funding for Jinarc so that those patients with ADPKD for whom the drug is deemed suitable by their nephrologist have the opportunity to have a better life. We have informed our consumers of this application and have advised them of the opportunity to provide feedback via the PBAC process. We know that this is an issue of great importance to people with PKD and their families and carers. We urge the PBAC to consider the consumer submissions that will tell the true story of the impact of PKD and the urgent need for access to treatments.

Yours sincerely,



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