Christopher Payne, patient expert – nominated by the National Kidney Federation

Cinacalcet Hydrochloride

Comments on the Appraisal Consultation Document

i) Whether you consider that all the relevant evidence has been taken into account

This is only based on my experience of taking Cinacalcet and the cost savings to the NHS.

I was approaching the time when the only treatment for my hyperparathyroidism would be a parathyroidectomy. In common with most long-term kidney patients (I have had chronic renal failure since June 1983) dialysis like old age does not come alone. Our respiration suffers, our hearts get weaker, and strokes become more likely making surgery a risky business. I was prescribed Cinacalcet and within two weeks my phosphate and calcium had dropped to acceptable levels and my PTH was coming down. I was taking 30mg daily.

Previously I needed to take large quantities of phosphate binders in a vain attempt to keep my phosphate down. I could only take a limited number of calcium-based binders for fear of hypercalcaemia I had been prescribed Renagel (sevelamer) and was taking 9 to 12 tablets a day.

Cost of Renagel (sevelamer) £6.80 to £8.16 per day
Cost of cinacalcet for me £4.57 per day

Now that I am taking cinacalcet I can keep my calcium and phosphate under control with just calcium based phosphate binders
For this reason I have stopped researching into expensive non-calcium based phosphate binders such as lanthanum carbonate.

Other drugs prescribed to dialysis patients to try to control hyperparathyroidism and hyperphosphataemia must also be taken into account against the cost of cinacalcet. Alfacalcidol for example and I am sure there are many others.

Before taking cinacalcet I was having difficulty walking, in fact I was taking the car for a journey of less than ½ mile to the village centre for my daily newspaper, the bone pain was too much. If as seems likely my mobility had got worse, even to the extent of needing a wheelchair, I would have needed hospital transport three times a week for dialysis at huge costs to the NHS.

I do not think that the costs to the NHS of not prescribing cinacalcet have been taken into account.

I cannot speak for other patients but taking cinacalcet has been a life changing experience for me.