

RECORD OF CONSUMER HEARINGS

Consumer meeting with Parenteral Nutrition Down Under about the requested Section 100 (Highly Specialised Drugs Program) PBS listing for teduglutide (Revestive®) for the treatment of patients with Type III (chronic) intestinal failure associated with short bowel syndrome. (Item 7.08)

Context

For consideration at the July 2018 PBAC meeting, Shire Australia Pty Ltd lodged a major resubmission to request a Section 100 (Highly Specialised Drugs Program) Authority Required listing of teduglutide for the treatment of short bowel syndrome (SBS) in patients who are dependent on parenteral nutrition for survival.

At the November 2017 PBAC meeting, the PBAC did not recommend the listing of teduglutide for the treatment of patients with Type III (chronic) intestinal failure associated with short bowel syndrome on the basis of an unclear clinical place in therapy and the very high and uncertain incremental cost-effectiveness ratio. The public summary document is available [here](#)ⁱ

Record of the meeting

The meeting discussed the upcoming July 2018 PBAC consideration of teduglutide for the treatment of patients with Type III (chronic) intestinal failure associated with short bowel syndrome. A representative of Parenteral Nutrition Down Under (PDNU) provided their perspective to the PBAC representatives about the condition and its impacts.

The representative of PDNU noted that a reliance on parenteral support has a significant impact on a patient's quality of life, due to:

- the time impact including while connected to parenteral support (e.g. a patient may be connected to parenteral support for 12 hours every day, which would occur overnight) plus the time taken to connect and disconnect, organise supplies and logistics, attend medical appointments, and (if applicable) care for a stoma;
- the worry of infection;
- immobility while connected to the infusion pump and bag and the weight of the infusion pump and bag (which can be carried by backpack, trolley or IV pole) especially given the fatigue associated with the condition;
- interrupted sleep due to toilet visits and pump alarms;
- dehydration and lack of energy;
- social impact including limited ability to leave the house in the evening or go away on holidays; and
- carer impact.

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The PDNU representative indicated that a reduction in the number of days of parenteral support required, and to a lesser extent the volume required, would potentially reduce the time impact, immobility and interrupted sleep while connected to parenteral support, and also reduce the social and carer impacts. The representative highlighted that the most meaningful impact would be a full night off parenteral support.

ⁱ <http://www.pbs.gov.au/info/industry/listing/elements/pbac-meetings/psd/2017-11/teduglutide-psd-november-2017>