



Jason Wood MP
Federal Member for La Trobe

MEDIA RELEASE

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Progress on listing of Soliris on PBS



It has been a long journey thus far for Grandmother Jenny Scott and Mother Linda Van De Loop. Jenny's granddaughter Bianca, and Linda's daughter Holly both suffer from aHUS (Atypical Hemolytic Uremic Syndrome), a very rare and life-threatening syndrome which is treatable with Eculizumab, or Soliris as it is most commonly known.

Jenny first came to Jason Wood MP back in January this year with her concerns of how Bianca would gain access to Soliris when it costs approximately \$500,000 per annum for treatment of one recipient alone.

"When it comes to helping out with life-saving medication, I'll always fight in a resident's corner. Jenny needed to get Bianca the Soliris that would help save her life, so of course I wanted to see what could be done for Bianca and other aHUS sufferers." Jason Wood MP said.

Under the *National Health Act 1953*, the Australian Government cannot list a medicine on the PBS (Pharmaceutical Benefits Scheme) unless it has first been recommended by the PBAC (Pharmaceutical Benefits Advisory Committee). So although Jason Wood MP met with Alexion Pharmaceuticals, who manufactures Soliris in order to see if the drug could be provided on compassionate grounds, it was clear that a decision needed to be made by the PBAC independently before funding could be arranged for Soliris to be available to those who need it.

Following the PBAC meeting in March, their decisions were published on the 28th April 2014.

Jason Wood met with Jenny Scott, Linda Van De Loop and Holly Van De Loop to share the good news today.

Jason Wood MP said “It’s great to hear that the PBAC has recommended Soliris to be listed on the PBS, news that we’ve been waiting to hear for a while now.

“Unfortunately though, we’re only about 50% of the way through the process.

“A positive PBAC recommendation is a very important step in the listing process, but other steps need to be taken before a listing is achieved. Pricing negotiations, finalisation of the condition for listing, and quality and availability checks all have to be done before we can breathe a full sigh of relief” said Jason Wood MP.

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