



PARLIAMENT OF AUSTRALIA

HOUSE OF REPRESENTATIVES

STATEMENTS BY MEMBERS

Atypical Haemolytic Uraemia Syndrome

Monday, 3 March 2014

Ms MACKLIN (Jagajaga) (13:30):

I draw the House's attention to the inspirational story of Katherine Marshall and her family who live in my electorate. Katherine is 23 years old and has been fighting an extremely rare immune disease, Atypical Haemolytic Uraemia Syndrome or aHUS, since 2010.

When I first met the Marshall family in 2012, Katherine was consigned to a life at home, besieged by constant fatigue and endless trips to the hospital.

Her family and physicians drew my urgent attention to Soliris, a drug produced by Alexion Pharmaceuticals. Alexion has been gracious in providing a compassionate access supply of Soliris to Katherine. The effect on Katherine was immediate and positive. In her father's, Gary's, words: 'She is a totally different girl now.'

Since then, the Marshall family have advocated for other aHUS sufferers, many of whom do not have compassionate access. They have established a support group and attracted national media about the need for aHUS sufferers to be covered for Soliris under the Life Saving Drugs Program.

This support group has run a national petition calling on parliamentarians to support funding for Soliris through the Life Saving Drugs Program for sufferers of aHUS. More than 22,000 Australians signed the petition, which was tabled in the House earlier today.

I want to commend their energy, compassion and sacrifice and to support their efforts in making sure that not only Katherine but other sufferers get access to Soliris.