

**From:**  
**To:** [Community Affairs Committee \(SEN\)](#)  
**Subject:** MPD patients and available treatments  
**Date:** Monday, 23 February 2015 5:31:56 PM

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hello,

I am writing to you to express a need in the area of MPD,S,  
many of us will need to change our medication as each one has a time limit for being tolerated by the  
body,  
and or more effective treatments.

currently we have very few to choose from, and we would like to be able to afford some of the  
treatments that are currently far too expensive here for public patients, but are having great success  
over seas.

**allowing MPN patients in Australia affordable access to Pegasys and Jakavi to be available to  
Australian patients would be life changing for many.**

**currently the drugs uses and that are on the pbs cause many side effects that prevent many of  
us form working.**

**hydrea for example takes 12 months for the body to get used to, and side effects diminish,  
however, we need to keep increasing our doses, as I have in my case every twelve months, so  
each added dosage creates more side effects.**

**many of us cannot tolerate interferon, as it causes depression in most people, and a lot of  
time in bed or vomiting, significant weight loss.**

**currently I have only these two drugs to choose from, both of which prevent me from having a  
normal life.**

**for example, I am divorced, with several children still in school, I cant go to bed early as I have  
to space out each of the three hydrea tablets in order to postpone the inevitable ulcers in the  
GI tract, which I have had previously. so I sleep poorly, in an attempt to sleep through the  
worst of the side effects, in the morning I cannot be more than 5 seconds away from a toilet  
as my bowel is volatile,**

**I cannot eat during the day if I need to shop etc, as it triggers a rush tot he toilet with limited  
capacity to wait, one minute would be too long.**

**my skin burns during the night , like 2nd degree sun burn, and clothing irritates it.**

**I have constant heartburn, and in the mornings my cognitive function is very poor.**

**I am not the only one who has to choose between two drugs , one of which I cannot tolerate at  
all, leaving me to lay on the bathroom tiled floor at 4 am when the burning of my skin gets too  
severe.**

**the bone pain is constant and there is little relief.**

**I would very much like to be able to try the drugs mentioned above, as my time on hydrea will  
end when I have to increase to 4 a day.**

**that is when I will run out of options,**

**i am one of many, that curenly is looking at a reduced lifespan directly impacted by the  
limited type of treatments available to me.**

**i do hope you will consider many of us will not be well enough to make a submission,**

kind regards



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