Patient story – use this to share with your friends, or you can turn it into a letter to send to your MP, the Minister of Health, your local paper etc.

**Date**

I am writing as someone who **is living with myeloma / loves someone who has/had myeloma** to explain the need to fund daratumumab, carfilzomib, pomalidomide, elotuzumab and ixazomib, and lenalidomide for earlier use in induction treatment.

I hope you will take the time to read this letter and that my story will help you understand the urgent need for these treatments, and the power you have in your hands to help people like **me / my partner / mother / daughter / grandparent etc** to stay alive and well **/ for my child / lead a productive life / continue to contribute to society / etc.**

**I / my (relationship and name if wanted)** was diagnosed with myeloma in **when**. *You could talk about where you were in your life at the time, eg little children, bought a new house, a new grandparent, working full time, just retired etc. You could talk about the impact the myeloma diagnosis has had on your life and your family, and the anxiety of not knowing how long you might live.*

*Talk about the treatment you have gone through so far and how it has gone.*

* *You may have found it hard to continue daily life with the side effects of thalidomide so could talk from experience about the need for more modern treatments.*
* *You may have been on a trial with daratumumab, pomalidomide or carfilzomib and can talk about the benefits of them from personal experience.*

*Talk about why you think we need more and better treatments for myeloma.*

* *You could talk about your family and why you need a better range of treatment options so you can be here longer for them.*
* *You could talk about how limited we are compared to other countries*
* *If you have considered moving countries for better treatment you could talk about that.*
* *It might be that you have had all available treatments so need more options, or that you haven’t had thalidomide yet but are worried about how the side effects would go for working/everyday life.*
* *Talk about the difference that daratumumab, carfilzomib and pomalidomide could make if you haven’t had them, and the difference that having lenalidomide instead of cyclophosphamide could have made in your initial treatment.*
* *You might want to talk about how these are available privately but at huge cost out of reach of most (eg daratumumab is approx. $220,000 in the first year).*

I hope this conveys why we need daratumumab, carfilzomib and pomalidomide, elotuzumab, ixazomib, and lenalidomide, for earlier use in induction treatment. *If you would like to, you could sum up your story and your key reasons for wanting better treatments.*

Name

Location

(both if wanted – if not, put anonymous).