

## **Draft Expert Patient Submission**

- Velcade has provided me with a treatment for my Multiple Myeloma that other treatments have failed to give. It has brought my paraprotein levels down and has encouraged me to accept further Velcade treatment so that a period of remission may result.
- The outcome of the treatment is to go into remission, or if this is not possible then to have a period of low paraprotein counts which will have a positive outcome on my longevity and on the quality of my life.
- The lowered paraprotein levels mean that I am experiencing less bone pain, my breathlessness has eased, blood transfusions are not needed, and I am taking fewer tablets, which used to make me feel ill.
- The treatment is uncomplicated and does not need me to be an inpatient or to spend a whole day as an outpatient ( max 2 hours per visit)
- My mental state is improved because I have had no hair loss, my appetite is good, I have not experienced huge weight gain or loss, so my social life has been maintained and I have a hope for the future as Velcade appears to be reducing my paraprotein levels.
- My kidney, liver and heart function has been good whilst on Velcade.
- My criticisms of the treatment is that my peripheral neuropathy has worsened, I have experienced a very high level of postural hypertension, constipation, extreme fatigue, poor concentration, and impaired reaction times.
- The above has led to my giving up driving, so the impact on my carer (wife) has increased, I need to have assistance when walking, which has led to reduced life style choices and less independence.

**Brian Jago**

- **As the Velcade treatment suppresses my immune system I have limited contact with friends and young family for fear of catching something.**
- **As the treatment creates a 4 day high ( dexamethasone is taken with the Velcade) and then a 3 day low (when the dexamethasone is stopped ) this means that for 21 days in the month I find social commitments are difficult.**
- **The dexamethasone taken alongside the Velcade means that I find it difficult to sleep whilst on the treatment.**

**Brian Jago**