Submission No 16

## INQUIRY INTO OFF-PROTOCOL PRESCRIBING OF CHEMOTHERAPY IN NSW

Name: Professor Barry J Allen PhD Dsc AO

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https://www.parliament.nsw.gov.au/committees/listofcommittees/Pages/committeedetails.aspx?pk=249#tab-termsofreference

## **Submission to the Parliamentary Committee**

I was treated by Dr Kiren Phadke for my stage 3 multiple myeloma in April 2015. The onset of an avalanche of symptoms (renal failure, infection, osteoporosis) caused by the myeloma left me seriously incapacitated, so Dr Phadke guided my wife through the complexity of my immediate management and choice of specialists. Stem cell replacement therapy was discussed but ruled out because of my age. Dr Phadke recommended Velcade and I achieved biological remission in 4 cycles of treatment without significant side effects. We did discuss having a further cycle but we decided that was not necessary.

I have nothing but praise for him and would recommend Dr Phadke to anybody else. I have every confidence in his judgement and the way he interacts with his patients. I have no reason to believe that he would not offer the best treatment to suit their needs.

I said on an ABC interview that Dr Phadke's patients should not panic because they have been in good hands. My experience was nothing but positive and patients should trust his judgement, even if the dosage they received went outside of recommended standards of treatment. Cancer therapy often involves subjective decisions in the light of a patient's condition, life expectancy and quality of life.

In my case I received the recommended dose, but I would hope that an oncologist would actually work in the best interest of his patient. If that happened to be outside protocol, so be it.

My treatment was very successful. This disease is not curable, but I enjoyed remission for 18 months. I will return to Velcade therapy and hopefully experience a similar response.

Prof Barry J Allen PhD DSc AO

Note: Professor Allen was formerly principal hospital specialist at the St George Cancer Centre and chief scientist at ANSTO. He was named one of the world's all-time top-50 medical physicists in 2013. He was appointed an Officer in the Order of Australia in 2015 for services to cancer therapy and medical physics. He developed targeted alpha immunotherapy for cancer in Australia and managed a world first phase 1 clinical trial for metastatic melanoma.