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**Sent:** Wednesday, February 13, 2008 12:14 AM

**To:** SANCO RARE DISEASES CONSULTATION

**Cc:** anja.helm@eurordis.org

**Subject:** Rare diseases

I am secretary of the Dancing Eye Syndrome support trust in the UK. I do have a comment to make on the consultation paper but I am not quite sure which question to relate it to, maybe number 1 'definition of rare'. Dancing Eye Syndrome (otherwise known as Opsoclonus Myoclonus Syndrome or Kinsbourne syndrome) is a rare disorder certainly satisfying the prevalence criteria. It is a paraneoplastic condition which means it is sometimes associated with neuroblastoma. A recent research grant application was turned down by the EU rare disease project. One of the reasons given was because cancer (the neuroblastoma) was not classed as a rare condition and Dancing Eye Syndrome could not be classed as a rare disease because of its association with cancer. In fact a lot of paraneoplastic conditions are rare and so maybe ought to have consideration.

Regards

Jane Stanton-Roberts

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