

David B Dunger
Professor of Paediatrics



Date:

Dear Dr

RE: Establishing a national register of young women with Turner Syndrome

Your patient has kindly agreed for her name and contact details being added to a national register of women with Turner's Syndrome. The register is being organised jointly by the British Society for Paediatric Endocrinology and Diabetes and the Society for Endocrinology. As well as agreeing to her contact details being released to the Register, she has also agreed that we submit basic data concerning the medical problems she has encountered during childhood and details of her various medications. The information will all be held securely by the British Society for Paediatric Endocrinology and Diabetes Clinical Trials Unit in Cambridge, under the supervision of Professor David Dunger.

The initial aim of the Register is to monitor provisions of clinical care provided to the young women during adult life through a simple annual questionnaire. However, in the future it is envisaged that the Society for Endocrinology will develop further research protocols for research projects which will be submitted for ethical approval. If approved, the young women will be contacted and their consent requested before their contact details are released to investigators.

We would be grateful if you could add this letter to the patient's file. If you need any further information please contact either Professor David Dunger (British Society for Paediatric Endocrinology and Diabetes) at e-mail dbd25@cam.ac.uk or fax number 01223 336996, Dr Malcolm Donaldson (British Society for Paediatric Endocrinology and Diabetes) at e-mail mdcd1t@clinmed.gla.ac.uk or fax number 0141 201 0837, or Dr Gerry Conway (Society for Endocrinology) at e mail g.conway@ucl.ac.uk or fax number 0207 380 9201.

Kind regards.

Yours sincerely,

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