

National register of young women with Turner syndrome

Turner syndrome is a common condition which affects around 1 in 2,500 young women. It is usually associated with slow growth during childhood and you may have had growth hormone treatment. Many young women with Turner syndrome also need help in the form of oestrogen replacement therapy to proceed through puberty normally. When you were young you may have attended specialist clinics where your growth was monitored but at the end of puberty, when growth is completed, you will probably have moved on to an adult clinic. We would like your help with a study which aims to get more information about the medical care that young women with Turner syndrome receive in adult life. We aim to do this by establishing a national UK Register of young women with Turner syndrome.



Who is organising the study?

The study was set up by the British Society for Paediatric Endocrinology and Diabetes (BSPED) which represents paediatric consultants like your own when you were a child. They look after young people with Turner syndrome and may prescribe growth hormone and early oestrogen replacement therapy. We are

asking for your help with this study on behalf of this charity. Your doctors will not receive any payment for your or their participation in the study. The register is co-ordinated by the BSPED Clinical Trials Audit Group in the University Department of Paediatrics at Addenbrooke's Hospital in Cambridge.

What happens if I agree to help with the study?

We would like your permission to keep some information about you in a database at the BSPED Clinical Trials Audit Group office in Cambridge. The confidential information we are asking for will include your contact details, information about your education and about your medical care now and when you were a child.

Your name and contact details will be stored in a different database to all the other information, so all your personal and medical information will be anonymous. We would also like your permission to inform your GP that you are participating in the study.



What do I need to do?

If you have not received a registration pack but would like to, please contact us at the address on the next page. If you have received a registration pack, we are asking you to fill in the enclosed consent form and the data collection sheet and return it to us in the



Freepost envelope provided. This data collection sheet asks some quite detailed medical questions and you might not be able to answer all of them, but please tell us as much as you can.

We would like your permission to contact your childhood doctor or nurse for the answers to any questions that you are not able to answer yourself. They will need to know that you have said it's alright for them to give us this information and we ask for your consent to contact him or her in the enclosed Register consent form. Send your completed consent form and data sheet back to us in the Freepost envelope provided. If you have not been able to answer some questions, we will then send on a copy of your consent form and a special medical data sheet to your childhood doctor for them to fill in.

What will happen when I provide my contact details?

The contact name and address that you provide will be held securely at the BSPED Clinical Trials Audit Group office in Cambridge. They will contact you each year to confirm that your contact details are still correct and to get an update on what medical care you are receiving.



Will anybody else have access to my information?

The medical information which is stored may be used for research, but your name and contact details will not be given out to anyone else. In the future, there may be investigators who would like to ask patients with Turner syndrome to be part of their research. If this happens, the proposals will be looked at carefully by the BSPED, or together with other interested societies and support groups. If they agree that the study is valuable, the BSPED Clinical Trials Audit Group will write to you to ask if you are interested in participating in such a study. Your contact information will not be given out unless you give us your permission first.

Can I change my mind?

If at a later date you decide that you do not want to be on the Register any more, just get in touch with the BSPED Clinical Trials Audit Group and we will make sure that we do not contact you again. This will not affect your medical care in any

way. We will keep any anonymised information which you have already provided, unless you ask us to destroy it when you leave the Register.

What is the next step?

Take some time to think about the study; you might want to discuss it with your family and if you wanted to you could ask your doctors what they think. If you decide that you would like to participate, please complete and sign the consent form to join the register and complete the data collection sheet. Return all the documents to the BSPED Clinical Trials Audit Group office in the Freepost envelope provided. If you would like some more information, or have not received a registration pack but would like to please contact the Clinical Trials Audit Group:

You could e-mail us:
turners@paed.cam.ac.uk
Or telephone us: 01223 769386
Or write to us at:
National Turner Register
Department of Paediatrics
Box 116 Level 8
Addenbrooke's Hospital
Cambridge, CB2 0QQ



British Society for
Paediatric Endocrinology & Diabetes



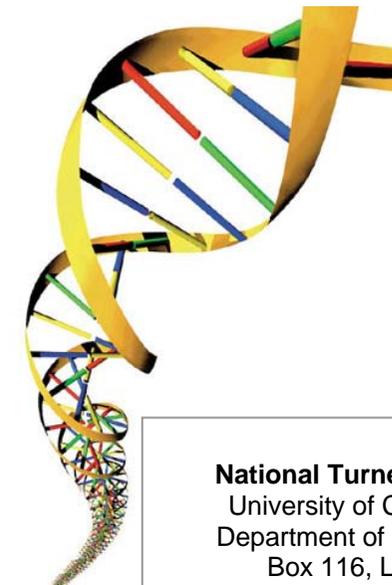
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CAMBRIDGE

Department of Paediatrics

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National Turner Register
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