



Do you have Klinefelter Syndrome (KS)?

You're not the only one... **Klinefelter Syndrome is a very common genetic condition in men**, yet many go undiagnosed and untreated. There have been many studies on the medical aspects of KS, but there is not much knowledge about how being diagnosed with KS might affect the person – the psychosocial impact. We want to change this. This sheet is an invitation to find out more about a study we are conducting.

Our study...

Andrology Australia, the national men's health organisation, together with the Murdoch Childrens Research Institute, Prince Henrys Institute of Medical Research and Monash University, want to understand more about KS. Your participation in this project is an opportunity to help. We want to ask individuals with KS how their lives have been affected by being diagnosed, and living with, various aspects of KS.

We are seeking individuals with KS aged 18 years and older, to participate in our study and share their views, opinions, experiences and stories of what it is like to be diagnosed with KS and to live with KS, including the good and the bad. Because features can vary greatly between people with KS, we are keen to involve as many individuals as possible - of all ages, stages, and walks of life. This includes people that may have been diagnosed when their mothers were pregnant with them (called prenatal diagnosis).

What does the study involve?

Participating in the study involves completing a written questionnaire (telephone assistance is available if required) of about 30-40 minutes. This asks questions about when and how you were diagnosed, what medical treatments you have received, family life, relationships, and how you feel about yourself and your body. **You will receive a gift card as a thank you for your time.** Participants will also be asked to provide a saliva sample and will be invited to participate in an optional interview (in person or over the phone).

Before you decide to be involved, more information on all parts of the study is available to you. Even if you agree to participate, you can change your mind about any part of the study, at any time.

I'd like to find out more – what now?

If you are interested in being involved – great! Fill in your details below, select one of the contact options and either mail or fax back this sheet to:

Amy Herlihy
Public Health Genetics, MCRI
10th Floor, Royal Childrens Hospital
Flemington Road, Parkville
Victoria 3052
Phone: (03) 8341 6370
Fax: (03) 8341 6212

Or if you prefer, give us a call or put the following details in an email to klinefeltersyndrome@gmail.com

Your name: _____

Signature: _____

Telephone: 1. _____ 2. _____

Address: _____

State _____ Postcode _____

Contact Options:

- Yes, please send me the Participant Kit by mail (this will contain further information about the study)
- Yes, please give me a quick call so I can find out more about this study

The best times to call me are _____

What if I'm not interested in being involved in this study?

That's fine too – You are not obliged to complete this form and we won't contact you unless you return it with your details. **We apologise if you have already received this information from another source.**