



ANDROLOGY AUSTRALIA

MONASH University



Murdoch Childrens Research Institute
Healthier Kids. Healthier Future.



Klinefelter Syndrome affects approximately 1 in 650 males. That represents almost 15,000 males in Australia - yet up to 70% of these cases remain undiagnosed, even though they may benefit from treatment.

Do you have patients with Klinefelter Syndrome?

Klinefelter Syndrome (KS) is the most common chromosome disorder in males (47XXY), yet most remain undiagnosed and untreated. Despite decades of work on the medical aspects of KS, little is known about how diagnosis with KS impacts psychosocially on an individual, and how this is influenced by age at diagnosis.

Andrology Australia, the national men’s health organisation, together with the Murdoch Childrens Research Institute, Prince Henrys Institute and Monash University, is undertaking a study to determine how treatments and interventions accessed at different ages affect adult biomedical and quality of life outcomes.

We need your help in contacting potential participants – men with KS, aged 18 years and older.

Because the features of KS are so varied, we want to involve as many men as possible, diagnosed at all ages – prenatally, in childhood, during adolescence or in adulthood. **We are particularly interested in participants diagnosed prenatally**, as there will not be as many men in this group who are now aged 18 years or older.

What does the study involve for the patient? This study involves completing a written questionnaire, providing a saliva sample for DNA testing and the option to participate in an interview.

We need your help to inform patients about our study...

What does the study involve for you? We will send you copies of the **Initial Contact Form** (attached), which you can either **mail to your patients**, or **give to them at their next consultation**. On this form, interested individuals can indicate their willingness to receive the study material.

Please return the following details by post, fax, in an email, or call on the phone number below:

- I have approximately _____ patients with Klinefelter Syndrome.
- Please send me _____ copies of the Initial Contact Form to distribute to my patients.
- Please send me _____ copies of the Study Information Poster to display.

Name: _____

Address: _____

Phone: _____ **Fax:** _____

Email: _____

For further information, please contact:

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Your assistance is appreciated