

A message from the Compiler

2010



You are not alone

Humanity is full of prejudice and fear of the unknown. If it's not common-place it's often viewed as alien; something strange, to shun, hide away and not speak about. With ignorance, assumptions are also rife.

I hope by creating The KS Story I can take the strangeness and uncertainty out of Klinefelter's Syndrome and help individuals, their spouses/partners and families – of all ages, to talk more openly about their feelings, to each other and to healthcare professionals.

I hope this guide helps people find the most appropriate advice and support, to guide loved ones through difficult times and to celebrate their differences, focusing on and being proud of their accomplishments.

And with sincere respect, I hope this guide helps healthcare professionals to understand more fully how Klinefelter's Syndrome affects their patients; to recognise their needs and preserve their dignity, and to know that the most appropriate and respected KS resources are just an e-mail or phone call away.

Welcome to 'The KS Story'

The KS Story was completed in 2005 as a book, but for various reasons was never published.

This year the book has been updated and is now offered as a pdf to Klinefelter's Syndrome support and allied organisations in the UK and Internationally, for anyone to freely view online, download and print off.¹ The pdf will be updated bi-annually.

This first edition (pdf) has a file size of 7.8 MB. For those readers with Internet Dial-up, I suggest you print off the sections you require, or ask someone you totally trust, who has Broadband, to download the whole pdf for you.

Healthcare professionals, Researchers, Study teams

For the benefit of healthcare professionals, I'm delighted and grateful to NHS Education for Scotland in accepting a pdf for their *e-Library* and to *nhs24.com* for including a hard copy at their headquarters library in Clydebank.

Your valued feedback & Further information²

theksstory@btinternet.com

Although I have made every effort to cover all angles and have sought appropriate contributor references and written approvals, I've learnt over the years that I will never please everyone.

I would therefore greatly value your feedback on anything which can improve the book in forthcoming updates!

Additionally, if you truly wish *The KS Story* to reflect International facts and attitudes, please email *concise* details and a reference where the information can be validated and I will do my utmost to include it in future updates. You can also send support group contact details.

For those involved in medical research, studies or documentaries specific to Klinefelter's Syndrome or related subject material, or if you wish participants for the latter, please contact the appropriate support groups, who have highly knowledgeable committee members. *Contact details start on page 74.*

If you would prefer an A4 no-frills black & white version of the book, let me know and if sufficient interest is forthcoming I will produce the artwork.

Please also read '*Furthering knowledge of Klinefelter's Syndrome*' on page vii.

Your interest in the *The KS Story* is truly appreciated and I hope you find it of value.

Regards,

A handwritten signature in black ink, appearing to read 'Iain'.

Iain W McKinlay 47,XXY

- 1) Please consider the environment before printing off the whole book. Why not download the pdf and keep on a hard drive, CD or memory stick, with your other Klinefelter's Syndrome resources?
- 2) Please don't use the feedback address above to ask about your symptoms, I am a graphic designer and not qualified to give advice on health issues. For that you should contact your GP (MD) or an appropriate support group or clinic. Thank you.