

Dear Member,

At this year's conference one of the greatest encouragements to new members was finding out that they were not alone in the questions they were asking. It was suggested that the time had come to begin collecting information that might be of value to all members and their families. However, as you will be aware, there is so much that we need to find out and we cannot do all that at once.

Attached to this letter is a questionnaire that forms the first stage in this research process. The questions are aimed at highlighting the key areas that *you* believe should be addressed by future research; we do not expect to throw up many answers at this stage, but it would help to have a clear idea of what questions *should* be asked next.

When we have received all your replies and analysed what you have said we will proceed to the next stage. This begins with letting you know the results, then informing the wider research world that Klinefelter's Syndrome exists and affects the lives of real people all around us and that more research is needed. We are looking for answers beyond the medical diagnoses, we are seeking to help and encourage families in their daily lives at school, home and work. We aim not merely to tackle difficulties but also to look for common strengths.

Members may well have found many answers already, but now we need to share those experiences and consolidate them in a way that will be of benefit to all. Please take time to answer as many questions as possible. You will note that the responses may be kept anonymous, however if you include a contact name or number this will help us ensure that we make the most of the information you send by following up specific points that arise (questionnaires are a very poor means of finding detail). Confidentiality will be maintained at all times, names will not be included in the analysis. Your contribution is vital, I urge you to return your completed questionnaire as soon as possible. Please do not hesitate to contact me should you have any further enquires about this process.

Yours sincerely

**XxxxXXXXXXXXXX**

**Section 1 - General Information**

1. What is your relationship to the person with Klinefelter Syndrome? (Please Tick)

I am the person with Klinefelter Syndrome	Wife	Mother	Father	Both Parents	Other (Specify)

2. What age is the person with Klinefelter Syndrome? (Please Tick)

0-2	2-4	5-7	8-11	12-16	17-24	25+

3. At what age was Klinefelter Syndrome diagnosed (medically)? (Please Tick)

Pre-birth	up to 6 weeks	First year	1-4	5-10	10-15	16-24	25+

4. What form of Klinefelter Syndrome has been identified? (Please Tick)

47XXY	48XXXXY	49XXXXXY	Mosaic	Don't know	Not prepared to say	Other

**Education** (if the subject is too young, please skip to the next section)

5. Please tick against any of the following schools that the subject attended

School/College	Main stream	Special needs	Other (please state)
Pre-school, e.g. nursery unit			
Infant			
Junior/middle			
Secondary			
Post 16, e.g. college, University			

6. Was a *Statement of Special Educational Needs* issued? (Please tick & state age)

Yes, at age....	No	Not yet	No, but unsuccessful attempts were made	Don't know	Other: state reason, (e.g. did not exist)

7. Please attempt to give an indication of performance in the following key areas in relation to siblings/peers (Please tick one box per subject)

Subject	Excellent	Good	Average	Weak	Very poor
Maths & Sciences					
Music					
Reading					
Speaking					
Handwriting style					
Art					
Memory for facts					
Sport/P.E					

8. How effective/helpful has schooling been in meeting the subject's learning needs?

Very	OK	No help at all	unsympathetic	Some helpful staff	Good at crucial times	Other

9. Please make any other comments that you feel are vital regarding any aspect(s) of schooling/education that you feel is important or worth emphasising

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**Personality/Behaviour**

10. Please tick any of the following personal characteristics that make the subject stand out from his peers/siblings.

Kind		Concentrates well		Disciplined		Reads social cues	
Sympathetic		Poor concentration		Happy		Misses social cues	
Many friends		Few friends		Naughty		Poor self esteem	
Hard working		Aggressive		Miserable		Well behaved	
Loves fun		Sense of humour		Sensitive		Easily led astray	
Lazy		Self controlled		Obsessive		Confident	
<b>Other:</b> please add to this row							

11. Has bullying been a part of the subject's life? (Please Tick any that apply)

Yes, was often bullied at school	Yes, was occasionally bullied	No, bullying has not been an issue	Yes, he often bullied others at school	Yes, he has bullied others occasionally

12. Please list/describe the activities that bring the subject great satisfaction & pleasure at home (e.g. if a child: playing with Lego, music, sport etc.)

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13. Does the subject have any obsessive behaviours?

Yes  No  (please tick as appropriate) If Yes, please give details:

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14. Please list any outstanding skills below

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15. Please make any further comments on general personality/behaviour below

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**General Health -**

16. Please indicate if the subject suffers frequently from any of the following common ailments, or regularly did as a child (Please Tick)

Migraine	Headache	Chest infection	Ear infections	Asthma	Sore throats	Others (specify)

17. How does the subject feel about sports? (Please tick all that apply)

Hates it all	Enjoys watching	Enjoys playing	Skilled at...(specify)	Poor at sport	No special feelings	Other

18. Please indicate any further comments or areas of research that you feel you would like answers to:

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Thank you for your assistance. Please feel free to add any comments or statements on a separate sheet.