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An extra X means extra worries?
Prenatal genetic testing: information needs and language used by new members in a Facebook group on Trisomy X

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Background
Results indicating a higher likelihood or a diagnosis of an extra X often cause significant distress in expecting parents. Some doubt about pregnancy continuation and all seek information and experiences. The Facebook group 'Triple X Syndrome/Trisomy X,' established in January 2016 is one of their resources. The author analyzed new group members and their wordings.

Methods
Author analyzed the membership requests from 2024 and assigned new members to categories.

Results
Accepted and still in the group are 371 members (86 were accepted and later left).
Prenatal: 33% of whom NIPT 13%, amnio/CVS 20%. 26% of the NIPT parents describe it as a diagnosis, 53% indicate uncertainty.The other 21% are like 'positive NIPT'.

The language used in membership applications and in the group, reflect the low level of knowledge about trisomy X, NIPT and chromosomes in general.

> 'We received a NIPT diagnosis'
> 'Will she be retarded?
> 'I told my daughter about the extra X gene'

Conclusion
Parents receiving prenatal test results have unmet information needs regarding trisomy X. Key information is the uncertainty that comes with NIPT, the variable outcomes of this condition and the fact trisomy X involves an extra chromosome rather than a single gene. Although peer support networks can provide information, better counseling before and after testing by professionals is also much needed.

> 'NIPT indicates a higher likelihood'
> 'She may have developmental delays, the range of outcomes is wide.'
> 'Trisomy X is an extra X chromosome, not just a gene'