

# An extra X comes with extra worries?

## Prenatal genetic testing: information needs and language used by new members in a Facebook group on Trisomy X

Jessica M. Langenhoff, MSc  
Contactgroep Triple X-Syndroom, The Netherlands  
Chromodiversity Foundation



### Introduction

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

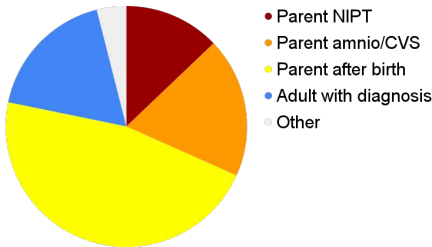
Author analyzed all membership requests received in 2024 and assigned new members to categories based on the reason they gave for their membership request.

A second analysis was done with the description the parents gave after receiving NIPT results. NIPT is no diagnosis, only indicates likelihood. Three categories were defined based on the (in)correct description of the test results.

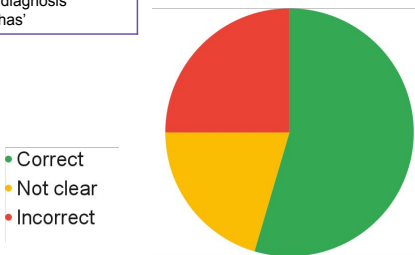
### Results

Accepted in 2024 and still in the group are 373 members.  
(84 were accepted and later left, their information is no longer available)

| Reason for membership | %  |
|-----------------------|----|
| Parent, NIPT          | 13 |
| Parent, amnio/CVS     | 19 |
| Parent, child is born | 47 |
| Adult with diagnosis  | 18 |
| Other                 | 4  |



| Parental description of NIPT                               | %  | Example                                    |
|------------------------------------------------------------|----|--------------------------------------------|
| Correctly reflecting the uncertainty of NIPT               | 55 | ‘indicating a higher risk’<br>‘might have’ |
| Not clear if parent understands the uncertainty            | 9  | ‘positive NIPT results’                    |
| Incorrectly stating certainty instead of higher likelihood | 11 | ‘NIPT diagnosis’<br>‘child has’            |



### Discussion

Parents receiving prenatal test results have unmet information needs regarding both NIPT and trisomy X. The language used in membership applications reflects lack of understanding of the uncertainty of NIPT and the lack of knowledge on trisomy X.

‘I am 12 weeks pregnant and was just told my baby has Trisomy X. Trying to learn as much as I can’

‘NIPT indicates a higher likelihood, it is not a final diagnosis’

Once parents are in the group, we see their anxiety for the unknown and the low level of knowledge about NIPT, trisomy X and genetics in general. It also shows thoughts on trisomy X.

‘Will she be retarded?’  
‘Do they look normal?’  
‘I told my girl about the extra X gene’

‘She may have developmental delays, the range of outcomes is wide.’  
‘Most girls do not have visible differences’  
‘Trisomy X is an extra X chromosome, not just a gene’

Key information for new members 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. In our group, we try to combine reassurance and personal experiences with evidence based factual information. Although peer support networks can provide this, better counseling by professionals before and after testing is also much needed.

A more detailed description of the methods is available on [www.xxs2info.nl/padua2025](http://www.xxs2info.nl/padua2025) or use the QR code

