

An extra X comes with extra worries?

Poster for Padua 2025 workshop, supplementary materials

Our group

Our Facebook group is called Triple X Syndrome/ Trisomy X. It is a private group, the title and descriptions can be found by all Facebook members but the content is for group members only.

When people apply for membership of our group, we ask them 'What is your connection with triple X syndrome (47,XXX)? Do you have it, your child or somebody else? ('yes' is not enough, we need some more information)'

We also ask 'How old are you? For 14 and 15 y olds, we ask a parent or caregiver is also in the group. Please mention their name if that applies.'

And we ask them to agree with the group rules.

Eligible for the group:

-Parents who received NIPT results, amnio/cvs results

not eligible: IVF/cryo embryo before pregnancy, we do not allow them in the group as it is too complicated for us to handle and gives very complicated discussions. 'I have an XY embryo and a 47,XXX one, would love to have a girl but...'

-Parents of children, after the birth of the child

Only those with a diagnosis are welcome. Parents who think their child may have this, are asked to come back after getting the diagnosis. We give links to AXYS and Chromodiversity websites.

-Adults with the diagnosis

Age: 14 and 15 y old when parent/caregiver is in the group, 16+ on their own

People who think they or their child may have this, are asked to come back after getting the diagnosis. We give links to AXYS and Chromodiversity websites.

-Others: family, professional

Not automatically eligible: vague or distant relationship with somebody who has trisomy X. Reason for this is bad experiences in the past (bullying). The person with the diagnosis or the parent can become a member and then invite the other person

Methods

Group analysis was done in April-June 2025, All applications between 1. Januari 2024 and 31 December 2024 were included in the analysis.

In the first round of analysis I counted the reason for application of group membership.

In the second round, for the subgroup of parents receiving NIPT results the literal reason for the membership request was copy-pasted and analyzed. In the second round, 3 errors in the first were corrected (2 were not counted, 1 was counted wrong)

Counting reason for membership:

Parent, NIPT

Parent, amnio/cvs

Parent, child is born

Adult with diagnosis

Diverse: professional, other family member, etc

Citing reason for membership in those who received NIPT results

Literal copy, sometimes extra information was left out (what they hope to find, where they live, how their family is).

NIPT correct = contains words indicating uncertainty like 'high risk', 'may have' etc

NIPT unclear = anything like 'positive NIPT result for trisomy X'

NIPT incorrect = mentions 'diagnosis' or does not contain uncertainty, like 'will have'

NA= Not Applicable: denied access, usually for incomplete applications

UN=Unknown: those who are no longer in the group, usually they decided to leave or their Facebook profile is no longer available

Possible issues:

-Counting a child double because both parents or other relatives ask for membership
There was one couple where one said 'my unborn daughter has it' and the other 'I got NIPT result'

-NIPT or amnio is not always clear. Assume amnio when parent mentions 'diagnosed' or 'has', unless it is impossible with the pregnancy duration (12-13 weeks)

-sometimes people mention 'child' in their membership request and then from their contribution in the group it is clear the child is not born yet

-if they are first denied then accepted they were counted as accepted. Refusal is usually for incomplete information or not agreeing with group rules

-when people leave the group (they decide to go) we cannot see their answers any more. So for most (those who did not post anything in the group) we will never know why they became a member. They may have ended the pregnancy, may have tested after NIPT and baby does not have trisomy X, baby has it but parents are no longer interested.

-removed from group: often because a FB profile is no longer available. Incidentally for bad behavior. These ones were left out of the analysis.