



Discussion Group Rules and User Agreement

(Adapted from longstanding LISTSERV rules embraced by all public groups)

Updated: January 30, 2015

- **Respect Privacy and Confidentiality.** Don't repost messages from this group without the author's permission. Do not harvest contact information for any purpose, and do not reveal information shared in these discussions anywhere outside these discussion groups.
- **Please keep posts on topic.** Each discussion group focuses on a particular diagnosis and on issues surrounding one or more X and/or Y chromosome variation. There are other groups for other subjects. Discussion on unrelated topics drives group members away.
- **Don't Flame Others.** Flames are angry and hurtful posts—it's a term as old as the internet itself. Flames have no place in a support group and will not be tolerated.
- **Be Tolerant.** It's okay to disagree. It's NOT okay to attack other members personally. Be polite even when you're angry. If you're too angry to be polite, don't post, or send a private message or email instead.
- **Do Not Engage With Those Adding Abusive or Inappropriate Posts.** If you feel that someone's posts are abusive or violate these rules, contact the group Admin. Do not fan the flames.
- **Don't Discuss Politics or Religion.** We are a VERY diverse group, ranging from atheists to religious fundamentalists, and ranging from radical liberals to radical conservatives. None of those views are germane to this discussion! We have ONE thing in common – X and Y chromosome variations. Discussion on religious and political topics always seems to generate more "heat than light". There are plenty of other discussion groups for these topics. If you care to discuss politics or religion, subscribe to one of those. To be clear, it is OK to say, "Thank God my child recovered." It is NOT OK to say, "If not for the grace of God and His divine intervention, my child would not have recovered." It is NOT OK to say, "You or your child need God/religion, and God/religion will make life better for you/your child." Someone will take issue with that claim. Politics and religion are a bit like sexual harassment in the workplace. What matters is how OTHERS perceive what you say. Anything that may be perceived as proselytizing on either topic IS proselytizing. It is also NOT OK to launch into a diatribe demanding that someone who posts such a comment stop making such statements. Instead, bring your complaint to the group Admin for private intervention.

AXYS (formerly known as Klinefelter Syndrome & Associates – KS&A), is a 501(c)(3) non-profit organization whose mission is to help individuals with one or more extra X and/or Y chromosomes and their families lead fuller and more productive lives.

- Don't Advertise. Don't advertise your product, your service or your organization—or anyone else's. It is OK to make referrals to other groups, doctors, organizations, and so on, when they are related to the discussion, and it's OK to recommend products/brands that serve individuals with special needs (for example, seamless socks), but all other advertising will not be tolerated.
- Use Emoticons. Emoticons reveal emotions in your message. Text can be a very emotionless medium (you can't see the sender's expression) and easily misunderstood. This is especially true when using a mobile device where autocorrect can garble a message. Emoticons sometimes make it easier to gauge emotion and it's better to be explicit than misunderstood.
- Do Not Engage In Private Chat. Send chat via PM or email. Depending on the topic, some of AXYS's groups can generate lots of posts. If you want to talk off-topic – discuss the weather, tell your latest joke, share a radio station meme, tell someone about the latest Internet virus scare, etcetera – send it to them via private message or email...or post to your public wall. This material is a distraction in the groups.
- "Silent Majority". Discussion in virtually all internet support groups is dominated by a small minority of individuals. Remember that these are large groups, and you are speaking with MANY people. "Silence" does not signify "consent" or "agreement." Silence may reflect discomfort or disinterest. Be respectful of the fact that many are here to "listen" and learn.
- Adult Topics. Pornography of any type is not permitted. But, these groups are comprised of parents and adults with the conditions. In some cases the discussion inevitably turns to adult topics, including sex, genitals, reproductive issues, gender identity, intersex and more. These subjects are germane to the conditions. AXYS simply requires that the discussions stay on topic and that members be respectful of others' sensibilities on these sensitive subjects. If you start a discussion on an adult subject, be courteous and begin your post with a simple alert: "Adult Subject Matter."
- Do Not Post Copyrighted Material. Don't post copyrighted studies, new articles and other protected information. Instead copy and send the link to where the information is located.
- You Are REQUIRED to Identify Yourself. The group Admin requires subscribers to provide a complete, VERIFIABLE identity, including full name, address and phone number. These are closed groups, and AXYS makes every effort to ensure that the identities of group members and the things they discuss are kept private. Members of these groups have access to this private, often deeply personal information. While you may use a pseudonym in the group, the group Admins will know the real identities of those in the group, and there are no exceptions. The Admins will not reveal your identifying information to others in the group. New applicants will receive a detailed explanation of this policy along with the request to fill out an online form to submit the information.

- Blocking. Group members are not allowed to block any Admin. Admins routinely review the member lists, and any member who has blocked any Admin – for any reason – will be immediately removed from the group.
- Reporting. This is AXYS’s group. If you have a problem with person or post in the group, seek recourse with the Admins. Do not report these individuals to Facebook. You may block any member of the group (other than Admins) you wish, but if you report someone, they may be deprived of access to the group and Facebook over a misunderstanding. Activity in AXYS’s groups is at the sole discretion of AXYS and group Admins. If you do not feel that the resolution of your complaint is satisfactory, you may leave the group.
- Not Medical or Legal Advice. AXYS is a health advocacy, education, and support organization. AXYS and its officers, directors, and staff are not medical or legal professionals or providing medical or legal advice – regardless of the nature of the material we share. In all cases, it is the responsibility of the individual members of this group to seek competent medical care or legal counsel to address their personal needs. Furthermore, any mention or recommendation (or lack thereof) by anyone from AXYS or any member of this group referring to any professional of any type or any institution providing any service is for information only. AXYS is not a referral or rating service, and all mentions of professionals or institutions are purely for the convenience and education of group subscribers.
- Disclaimer and User Agreement. These groups are a free service of AXYS. While we may be able to moderate discussions after the fact, AXYS cannot control what users write, and AXYS disclaims responsibility for all messages. Furthermore, while AXYS’s discussion group rules prohibit any invasion of privacy or misuse of information shared in these discussions, AXYS disclaims responsibility for any misuse of information you share. Use of these groups constitutes users’ agreement that AXYS is not responsible for the content of any posting or misuse of information by any subscriber including those individuals who may be directly affiliated with AXYS.
- Violations and Recourse. Subscribers violating these rules may have their posts rejected or removed, and continued abuse may cause the offending party to be suspended from participation or permanently removed the discussion group. Repeating for emphasis: Activity, membership and participation in AXYS’s groups is at the sole discretion of AXYS and group Admins.