

4P- Support Group Privacy Policy

Our commitment:

The 4P- Support Group was established as an organization that would provide information to families with a child who has a 4th chromosome abnormality and to provide opportunities for families to connect with one another.

The Board of Directors is committed to continuing and expanding opportunities to get information to the families of 4P- children while ensuring that we protect each family's privacy.

Information to be collected:

Upon inquiring for membership with the group, the President collects certain information from the family. The following is a list of that information that would be shared with Regional Directors of the 4P- Support Group.

- Parent(s) name
- Complete mailing address
- Phone number
- Email address

It is the family's right to choose which information they will submit, without fear of not obtaining membership to the group or to receive all information available to the membership body.

Purpose of collecting this information:

By collecting this information, the 4P- Support Group is able to serve the families in the manner for which it was established.

The information collected allows the group to send quarterly newsletters, provide a listserv for open communication, and notify families of gathering opportunities to meet other families with a 4P-child(ren).

Who the information will be shared with:

The President's job is to maintain a database of families and to help maintain each family's privacy and to be the primary contact person for any business contacts. Privacy of each family is of extreme importance to the Board of Directors.

The President will share information with the Regional Director in charge of your specific region, ***unless you elect otherwise via a written request to the President.*** The Regional Directors are held accountable for keeping this information private to themselves and not sharing information outside of the organization.

By extending the contact information of families to the Regional Directors, the organization is hoping to have better communication and giving families more notice of gathering opportunities. Contact with families is to happen only for the purposes of sharing regional gathering information, special events the regional director may have knowledge about, and fundraising opportunities for the 4P- Support Group.

Your rights:

You have the right to cancel your information to be shared or change which information you want shared. A written request must be sent to the President of the group to have any information changed. (see contact us section)

If you choose not to have information shared with your Regional Director, you will still be notified of upcoming events and still receive the information available to all others. **Please contact Amanda Lortz, President, if you DO NOT want your information shared.**

If you feel that your information has been used in a manner not addressed in this policy, please contact the President immediately, so corrective action can be taken.

A copy of the 4P- Support Group Privacy Policy will be available on our website, www.4p-supportgroup.org and will be mailed to you annually.

Accuracy of information:

The 4P- Support Group is committed to maintaining the accuracy of your personal contact information. If at any time you notice an inaccuracy in our data or if your personal contact information changes, please notify us immediately (see contact us), so we can make the necessary changes.

Use of Appropriate Safeguards:

The 4P- Support Group Board of Directors are all elected positions, voted on by the general membership. Regional Directors are chosen by the members in their region. With the election process, members are choosing individuals they trust to serve the organization in the best way possible. The 4P- Support Group has limited control over the Regional Directors' use of the information they will be given. The Board of Directors does strongly emphasize to the Regional Directors the proper use of the privileged information they have access to.

The Board of Directors is only able to monitor how the Regional Directors' use this information by the communication seen going out to the membership and by the membership's communication with the board of what contact the Regional Director is making with them. Please feel free to communicate with any board member on this issue.

If the Board of Directors discovers that any Regional Director is misusing the personal information they are given, the Board of Directors will immediately remove that person from their position as Regional Director.

Contact us:

You can contact the 4P- Support Group via the President at:

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