

# Welcome to the FamilieSCN2A Global Support Network

We are a registered 501(c)(3) organization created by parents of children diagnosed with rare forms of *Epilepsy* and *Autism* as a result of a change in the SCN2A gene.

Our **vision** is to find effective treatments and a cure for SCN2A related disorders.

Our **mission** is to improve the lives of those affected by SCN2A related disorders through research, public awareness, family support and patient advocacy.

To meet the growing needs of our online private group members;

The FamilieSCN2A Foundation maintains

1 Public Facebook Page and 6 Private Facebook Groups for our SCN2A Families:

- a. FamilieSCN2A Global Network
- b. SCN2A Autism Network
- c. SCN2A Epilepsy Network
- d. SCN2A Teen & Adults Network
- e. SCN2A Grandparents Network
- f. SCN2A Bereavement Network

Information about the FamilieSCN2A Foundation & SCN2A: [www.scn2a.org](http://www.scn2a.org)

## FamilieSCN2A Foundation Board Members:

Leah Schust - Executive Director, Past President, Founder & Research Chair

Carla Forbes - President, Co-Founder & Global Network Chair

Michelle Lewis - Vice President

Jennifer Burke - Secretary

Mike Vasey - Treasurer

Will Hutson - Director At Large, Research Committee

Emily Park - Director At Large, Research Committee

Maura Bragg - Director At Large

Catalina Betancur - Director At Large

Mery Oman - Director At Large

The FamilieSCN2A Foundation is always looking for volunteers in our growing committees. Email us at [info@scn2a.org](mailto:info@scn2a.org)

## Group Rules

1. Share experiences, not medical advice. Never disregard or delay in seeking professional medical advice. Please consult your physician with any questions or concerns.
2. All members of this group are caregivers to loved ones with an SCN2A Disorder. We all struggle in many ways, including financial, so we ask you to refrain from posting about personal fundraisers within the group. The only fundraisers allowed to be advertised in the group are ones directly benefiting the FamilieSCN2A Foundation.
3. Administrators will review each member request carefully before approving their admittance to the group. Requests from anyone that is not a parent or caregiver of an SCN2A affected child will be ignored. Our goal is to make this a safe place to share, so we only admit direct caregivers to a patient with SCN2A Disorder. If you would like to have an extended family member (grandparent, etc.) please let us know.
4. To reduce bias, parents who are employed or have a financial relationship in the medical research, biotech, pharmaceutical or other related industries must disclose this information and admission to the group will be considered on a case by case basis.
5. Administrators have the right and responsibility to remove any member who becomes disruptive or who does not respect the culture of this group. Bullying will also not be tolerated. In light of the state of the world due to Covid19 and the political and racial controversies at hand, we ask that everyone refrains from posting or commenting on this topic. Let's make an effort to keep our group focused on SCN2A.
6. Posts that serve to solicit or recruit members are prohibited. In addition, sharing and/or copying information from posts is prohibited unless otherwise stated. We encourage sharing of posts from the Foundation's public Facebook page.
7. Sharing of research projects / opportunities to participate are welcome however must have an IRB approval. It is the Foundation's responsibility to verify this information.
8. At no time should any member post any identifying personal information (ie: address, date of birth, social security number or credit card information.) Requests for member's information, data & other research-related questions must be pre-screened by administrators. Administrators may elect to remove any post that violates this rule.
9. Statements made by members of the SCN2A Support Group do not reflect the views or opinions of the FamilieSCN2A Foundation, officers or directors, and the FamilieSCN2A Foundation shall not be liable for any injury or damages you may suffer as a result of your reliance on any information posted in the group, including information posted by the group's administrators.

# FamilieSCN2A Global Support Network Policy

## Terms of Use for the Global Support Network & Sub Network Groups

### 1) Purpose of the Group

- a. The Global Support Network is a Facebook group established by the FamilieSCN2A Foundation for parents, caregivers, patients and families of children with SCN2A related disorders. The purpose of the group is to create a community where affected families can turn for support and guidance from others in similar circumstances
- b. All support groups and discussion forums moderated by FamilieSCN2A follow the same procedures and Terms of Use.

### 2) Administration of the Group

- a. The administrators of the groups, at all times, will be two or more of the current board members of FamilieSCN2A, as well as FamilieSCN2A Staff/Volunteers.

### 3) Requirements for Joining the Group

- a. You must fill out the form to enroll in the **FamilieSCN2A Global Support Network** <https://airtable.com/shrBHDnKGQYz4Hhot> and agree to the “Terms of Use” for our support groups. We respect your privacy and information submitted in this form will not be shared with third parties outside of FamilieSCN2A.
- b. You will need to request to join the Facebook group [here](#). A group admin will then work to confirm your identity and admit you into the group. If you do not receive notification of your approval in 2 business days please email [community.support@scn2a.org](mailto:community.support@scn2a.org)
- c. Our administrators may ask for additional identifying information in order to verify that you are a real person who could be located outside of Facebook. Requests that can not be verified will be deleted after 30 days.
- d. In order to join FamilieSCN2A-moderated support groups on Facebook and to allow all of our members to feel they are part of an authentic community, FamilieSCN2A requires that participants use a Facebook account that does not conceal their true

identity. Facebook accounts that do not meet the guidelines below will not be permitted to join the group:

- You may not pretend to be anything or anyone other than yourself.
- Your account name may not contain offensive or suggestive words of any kind.
- The intent of this policy is to protect the group from imposters. If at any time the administrators become aware that a particular group member has falsified his or her identity, they will be removed from the group.
- The administrators may occasionally allow someone outside of these requirements to join the group for a variety of reasons. The decision whether or not to allow such individuals to join the group is solely at the administrators' discretion.

#### **4) Requirements for Posting in the Group**

- a. All posts and comments in the group must be courteous and respectful to other group members. If the administrators determine that a post, comment or thread lacks (or could be construed to lack) the requisite courtesy and/or respect, they may elect to remove the post, comment or thread from the group.
- b. At no time should any member of the group post any identifying personal information, such as his or her address, date of birth, social security number or credit card information. Such information similarly should not be shared with other group members via Facebook message or any other form of communication unless the group member providing the information has a relationship with the recipient outside of the group and/or has some independent method of verifying his or her trustworthiness. Should a group member elect to share such personal information, FamilieSCN2A is not liable for any loss or injury incurred as a result.
- c. At no time may any member of the group post any information that is untrue or misleading in any material respect. Nor may any member of the group provide false or misleading information to other group members via Facebook message or any other form of communication. The administrators, in their sole discretion, may elect to remove any post or comment that violates this policy or to remove any member of the group who has falsified information.
- d. Group members may not use the group to promote fundraisers or solicit donations for organizations other than the FamilieSCN2A Foundation. The administrators, in their sole discretion, may elect to remove any post or comment that violates this policy.

e. If a post or comment is removed from the group, the group member whose post or comment is removed will be notified of the removal by the administrators. The administrators may ask the group members to explain his or her conduct. If the group member fails to provide an adequate explanation or, thereafter, posts another message or comment that violates the policies described above, the administrators, in their sole discretion, may remove the group member from the group.

f. If any group member has concerns about the propriety or veracity of posts or comments made by another member, he or she should send a message expressing his or her concerns to one or more of the administrators. The administrators take all such reports seriously and will do their best to investigate the matter.

## **5) Privacy**

a. Although the SCN2A Global Support Network is a “closed” group and, as such, posts can only be viewed on Facebook by other group members, the FamilieSCN2A Foundation cannot prevent other group members from sharing any information that you post with third parties. Additionally, we reserve the right to cooperate with local, state and national authorities in investigations of improper or unlawful activities, and this may require the disclosure of your posts, comments or any other personal information that you have shared with the group. We may also report to Facebook or other organizations about improper or unlawful user activities, and this reporting may include disclosure of personal information relating to those individuals conducting such improper or unlawful activities.

## **6) Limitation on Liability**

a. The SCN2A Global Support Network does not provide medical advice, and at no time should you rely on any information provided in the group in lieu of seeking medical care from a physician. Similarly, statements made by members of the SCN2A Global Support Network do not reflect the views or opinions of the FamilieSCN2A Foundation or any of its officers or directors, and the FamilieSCN2A Foundation shall not be liable for any injury or damages you may suffer as a result of your reliance on any information posted in the group, including information posted by the group’s administrators.