

# What is RettNet?

The RettNet is provided at no charge by Rettsyndrome.org to encourage a forum for the free exchange of information on various aspects of Rett syndrome awareness, care, research, treatment and support.

To preserve confidentiality and foster a sense of community, participation in this group is closed to non-registered members.

As a registered community member, your use of RettNet is subject to the following terms and conditions. Should these terms and conditions be breached, you may be banned from further participation on RettNet.

## RettNet Terms and Conditions

### **I agree to engage in respectful discourse.**

The goal of RettNet is to offer a safe haven and support community. The posting of any defamatory, abusive, profane, threatening, offensive, or illegal content is prohibited. Any such content will be deleted and the user banned from further participation.

### **I agree to respect and be mindful of privacy considerations.**

Do not post anything on RettNet that you would not want the world to see or that you would not want anyone to know came from you. Please be aware that your posts will be linked to personal identifiers, including your user name. It is therefore important to be careful when disseminating personal information. This includes your name and phone number.

It is also important to be careful when posting about others, including relatives and, especially, children. Remember that posting may be permanent. Even if you delete a post, another member may include your post in a response to another member. It may then be forwarded by other members. It is advisable to weigh the benefits of participation on RettNet against the confidentiality considerations associated with sharing information.

Always pause before posting...

### **I understand that RettNet is not medical advice.**

Any message on the forum is for information purposes only, and may in no circumstances be construed as medical advice. If you have a medical emergency, promptly contact your health care provider. You should never disregard medical advice, avoid or delay visiting a medical professional, or deviate from any treatment program prescribed or otherwise recommended to you by a treating physician or other qualified health provider because of something you have read on RettNet.

THE INFORMATION OBTAINED THROUGH RETTNET IS NOT TO BE CONSTRUED AS PROFESSIONAL ADVICE, MEDICAL, LEGAL OR OTHERWISE FROM RETTSYNDROME.ORG.

### **I will avoid diagnostic conversations.**

The information posted by participants may not present a complete medical history, and members should not offer diagnoses to other members. Any information relating to a therapy or diagnosis—even if it comes from another parent that seems like an “expert”—must be received with caution. Only a physician is authorized to confirm a condition or diagnosis. RettNet must not, under any circumstances, delay or replace the advice of the treating physician.

### **I will avoid passing judgment on the treatment decisions or healthcare provider decisions of others.**

Treatment decisions should be made by caregivers and the treating medical team. Patient care and outcomes

are always dependent upon the particular case. The content found on rettnet cannot be substituted for consultation with a physician or other qualified health provider. Please confer with your physician before implementing any of the ideas discussed on RettNet.

The treatment choices of other patients must be respected and a member should never claim that a specific treatment is the only one to be effective or valuable, although it may be true for that one individual.

Remember that an individual's experiences at a particular hospital or with a particular treatment may not be representative of everyone's experiences. Do not engage in defamatory behavior against a treatment course, hospital, or physician. The goal of RettNet is to share and support only.

Thank you for keeping the topics Rett-related, and for keeping this an open and supportive environment for all participants.

### **Disclaimer**

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Rettsyndrome.org, a 501c(3) non-profit corporation registered as the International Rett Syndrome Foundation, is the most comprehensive non-profit organization dedicated to providing thorough and accurate information about Rett syndrome, empowering families, and stimulating research aimed at accelerating treatments and a cure for Rett syndrome and related disorders.

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