

## The Life After Rett Network

Many parents and family members that have lost a loved one with Rett syndrome have asked IRSF to provide a bridge to others who understand; to provide a place to share feelings of grief and loss, and to share strategies for coping, healing, and staying involved with the Rett community in a meaningful way. In response, we have created a private Facebook group named the Life After Rett Network. We invite you to join.

This group will allow you the opportunity to seek support, ask advice, address practical issues, and also allow you to serve as a pillar of support to others who may be going through a stage that you may have already experienced. This Facebook group will also allow you to discuss positive ways to commemorate your child through continued involvement with IRSF and the Rett syndrome community.

Please feel free to join the group by searching for "Life After Rett" on Facebook. As a private group, only members will be able to see and respond to posts. Members will not be able to view your personal information unless you choose to be 'friends' via Facebook. If you do not have a Facebook account and would like help setting one up, please contact us at [admin@rettsyndrome.org](mailto:admin@rettsyndrome.org) or by calling the IRSF office at 1.800.818.RETT (7388).

The group was founded and will be moderated by Jane George, whose daughter Aniko passed away at the age of 29 in 2005. Jane has continued her involvement with IRSF and serves as an ongoing resource to the Rett syndrome community. Jane confesses to feeling the pain of everyone who grieves due to Rett syndrome as she is still dealing with the loss of her own daughter, but believes that sharing these feelings and experiences is the path to renewed hope and a brighter future.

We are sorry for the loss of your child. We hope that you will join the Life After Rett Facebook group if you are interested in seeking and offering support in a community of others who understand.

Most Sincerely,

Paige Nues and all at the International Rett Syndrome Foundation