

# BECOME A LOCAL RETT REPRESENTATIVE IN YOUR NEIGHBORHOOD

As a local Rett Representative you can be an encouragement to other Rett Families in your area with helpful Resource Information and Friendship.

**Interested in Becoming a Local Area Representative For Alabama Rett Families?**

Alabama Rett Connect a representative of the Southeastern Rett Syndrome Alliance, is looking for motivated, dedicated and passionate people to become Local Area Representatives using the **11 PHA areas of Alabama**

**Mission Statement**

The PHA Representative program will provide supportive local contacts for families that have individuals with Rett syndrome, promote public awareness and knowledge of SRSA and IRSF, and connect families through gatherings and outreach.

**For more Information, Please Contact:**

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Or

Sheryl Hand @ 334-201-6718 or email [Sheryl@alabamarettconnect.org](mailto:Sheryl@alabamarettconnect.org)



“Every 2 hours a girl or boy is born with Rett Syndrome, but most people have never heard of it. Help others learn about Rett Syndrome”

## About the Support Program using the 11 PHA Areas

The PHA Representative Program has been established to provide emotional support, information and resources, plus maintain a support network of RS families in each area of the state.

**Each Local Rep will be encouraged to contribute in the following areas:**

You will receive a state registry of persons with Rett Syndrome that live in Alabama.

Provide resource information and emotional support to families in your area.

Reach out to new RS families that are in your area with a letter or phone call.

Plan at least one yearly get-together for the families, like a picnic.

Promote public awareness of Rett syndrome.

Encourage participation with SRSA, the UAB Center for Excellence, Rare Disease Center, Dr. Percy and IRSF.

Keep a list of families in your area, make sure families sign a waiver form if they want to be placed on the state registry. Share names of new RS families with ALRC, IRSF, SRSA, and UAB Dr. Percy. Stay in contact with the Program Director of Alabama Rett Connect by submitting monthly reports with new names that you have, and share information about activities from your area.

**\*\*PLEASE DO NOT SHARE INFORMATION ON FAMILIES WHO HAVE NOT SIGNED A RELEASE WAIVER**