

April 12, 2019

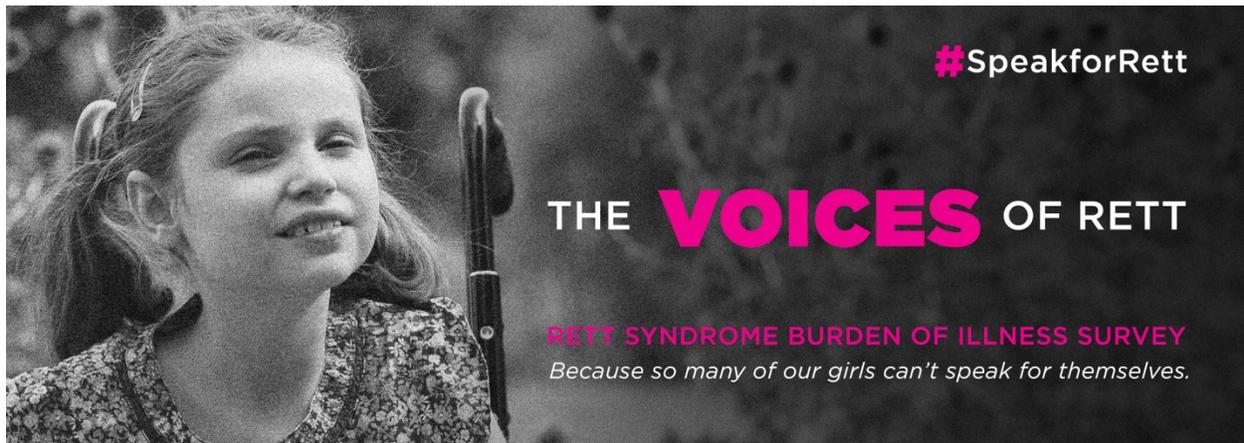
Paige Nues
Director of Family Empowerment
Rettsyndrome.org
4600 Devitt Drive
Cincinnati, OH 45246

Dear Paige:

Newron Pharmaceuticals wishes to thank RettSyndrome.org; patients/families and physicians whom have unselfishly supported the clinical trial to advance treatment in Rett disease. Newron Pharmaceuticals recognizes that the approach to orphan-drug development differs from the development of new treatments for larger populations. It also carries significant challenges, particularly in terms of clinical trial design and implementation. Working in collaboration with RettSyndrome.org, Newron Pharmaceuticals would like to update all Rett families on the present status of the Newron STARS trial, assessing sarizotan effect on respiratory breathing abnormalities.

The clinical trial enrollment has been completed. For those patients most recently added to the trial, they will complete in (6) months. The data will be compiled, and the trial effect will be available during 4th quarter 2019.

The trial has already produced new learning's linked with respiratory breathing abnormalities collected through baseline patient screening data. These data imply that breathing abnormality; frequency, severity and life-persistency exceed prevalent established presumptions. These learning's together with the trial use of a wearable respiratory monitor will provide the Rett community with objective real-life data to precisely measure drug treatment effect in the real-world setting.



While waiting for trial results, Newron Pharmaceuticals continues our collaboration within the Rett community. It's about actively listening – not just around a product – but for what it is that patients and families need. Toward this end, Newron will launch an International Burden of Disease survey across (6) countries, called “The Voices of Rett” (*because so many can't speak for themselves*), in May 2019. This important survey is your chance to lend your voice and make a difference. This comprehensive survey will be implemented in the US through Rettsyndrome.org to help raise awareness, educate decision makers and support the need for treatment. Many of your girls with Rett Syndrome can't speak for themselves, but you can!

Working in concert with caregivers, advocacy groups, physicians and government our expectations are high. Our promise to the Rett community is that we will strive to engage you in a meaningful way. To know even one life has breathed easier, this is to have succeeded.

Sincerely,

Dennis Dionne

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