

Subject: Rett syndrome Community Statement

Dear Rett syndrome Community,

We at Novartis Gene Therapies hope that you and your families have had a good start to 2021, and we would like to begin the year together by expressing that we deeply appreciate your collaboration and partnership and providing you with an update on our OAV201 program for Rett syndrome.

Our advocacy partners are strong allies who have deepened our understanding of this disease as we advance promising science with transformative potential for Rett. We have been fortunate to partner with Rettsyndrome.org and Rett Syndrome Research Trust on awareness initiatives like October Rett syndrome Awareness Month, presentations to our colleagues by Rett advocacy leaders, registry, biomarker and outcome development, and support of educational programming.

As we indicated in our last update, we have been working closely with the FDA to progress OAV201 towards an Investigational New Drug (IND) application. Today, we are pleased to let you know that we expect to submit an IND by the end of the year. As a reminder, an accepted IND is required before we can proceed to clinical trials in patients with Rett syndrome.

We recognize the significant unmet need among patients with Rett syndrome and want to again assure the Rett community that we are fully committed to pursuing a gene therapy for Rett syndrome, and that we are continuing our work with a sense of urgency and purpose.

We look forward to continued partnership with the Rett community and commit to providing you with updates on a regular basis as we have more information available to share.

Sincerely,

The Novartis Gene Therapies OAV201 Development Team

US-UNB-21-0003 2/2021