

# Results of the Rett ORCA Study: How Rett Families Are Impacting Clinical Trials

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# Results of the Rett ORCA Study: How Families are Impacting Clinical Trials



**SPEAKER**

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**HOST**

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# Rett ORCA is part of an overall strategy

## RSRT Initiatives Supporting Biopharmaceutical Companies

### Outcome Measures

*Generate Rett-specific measurement tools  
for key symptoms at FDA standards*

### Rett Syndrome Global Registry

*Expedite curative  
programs*

### Rett ORCA

*Rett-specific  
communication*

### Biosensors

*Sleep, breathing,  
heart rate variability*

### Non-clinical Initiatives

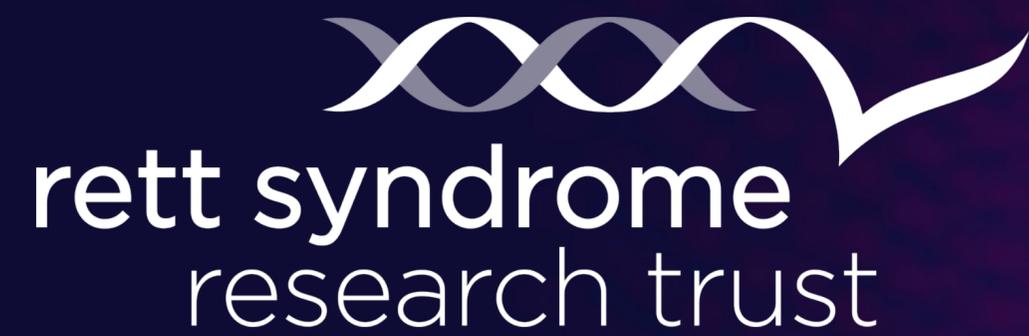
*Biomarkers &  
animal models*



# What are outcome measures?

- Measurement tools that rate a symptom
- Determine impact of the intervention
- Questionnaires, scales, diaries, functional tests, or physiologic measures
- How clinical trials assess efficacy
- Rett ORCA is the first Rett-specific scale to assess communication ability





[www.reverserett.org](http://www.reverserett.org)

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