

✓ IRB APPROVED

*All research has been approved by the Institution Review Board which consists of a committee that has been established to oversee the protection of human research subjects at Boston Children's Hospital. Boston Children's Hospital is committed to safeguarding the rights and welfare of all children, adolescents, adults and family members who volunteer to participate in research.*



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## Speech Generating Devices in Children with Angelman Syndrome: An Effectiveness Trial



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Sponsored by:  
The Angelman Syndrome Foundation





## What you may be wondering about our research study...

### **What is the purpose of our study?**

To examine the effectiveness of an intervention to teach children with Angelman syndrome how to use a speech generating device (SGD) to communicate.

### **How long will my child be in the study?**

Your child will undergo an initial developmental and communication evaluation. He or she will then receive 12 weeks of intervention twice weekly. A month after discontinuation of the intervention, he/she will receive four follow up visits. Participation is completely voluntary and you may decide to withdraw at any time without affecting your child's medical care.

### **Who may be eligible to participate in this study?**

If your child is between the ages of 4-15 years old and has a molecular diagnosis of Angelman Syndrome.

### **What will happen during the study?**

You will complete questionnaires about your child's current communication patterns to determine his/her eligibility for the study. If eligible, your child will undergo a developmental and communication assessment. Your child will then receive structured home-based intervention twice weekly for 12 weeks conducted by graduate students in speech and language pathology to teach him/her to use the SGD to communicate.

### **What are the benefits of participating?**

You will benefit from the results of the comprehensive evaluations where we will provide you with detailed information about your child's cognitive, language, motor and communication skills. Being part of the study will not impact any of the services your child is already receiving. We hope that the intervention will improve your child's ability to use an SGD to communicate.

### **Are there any costs involved in participating in the study?**

There is no cost to you and your family to participate in the study.

### **Will I receive compensation for participating in the study?**

The cost of parking is covered for the in hospital visit.

