



A New Way to Keep Track of Your Child's Progress

Every new parent looks forward to their baby's first step or first words. Now, parents can track their child's progress with a free Milestone Tracker app from the Centers for Disease

Control and Prevention (CDC). Use this free, parent-friendly app to track and celebrate your young child's development from ages 2 months through 5 years. See photos and videos that illustrate milestones. Try new activities to support your child's early development. Get helpful reminders for appointments, and more!

Although it's packed with parent-friendly features, this app is not just for parents! Healthcare providers can use it to help with developmental surveillance (regularly monitoring a child's development to identify problems with development early), as recommended by the American Academy of Pediatrics. Early care and early education providers can use the app to better understand their students' skills and abilities and to engage families in monitoring developmental progress.

The app is available in both English and Spanish. It has been culturally adapted for Spanish-speaking parents of young children, as *Sigamos el Desarrollo*.

To get the app, go to www.cdc.gov/MilestoneTracker, or click [here](#) to download from the App Store or [here](#) to download from Google Play.

"I love the photos and videos on Milestone Tracker. It helps me to know exactly what milestones my son should be reaching."

Jasmine B., mother of 1-year-old, Atlanta, GA



App GRATIS de los CDC Sigamos el Desarrollo

DISPONIBLE EN  **App Store**

DISPONIBLE EN  **Google Play**

Infórmese más en cdc.gov/Sigamos

Autism and Genetics

Autism spectrum disorder (ASD) is a complex condition that affects social skills, communication, and other behaviors. Despite improvements in our understanding of ASD, we still have a lot to learn about its causes and treatment. Studies indicate ASD has both environmental (meaning exposures, like a person's diet, medicines, or pollutants, which are external) and genetic causes.

Many types of genetic mutations (meaning changes in a person's genes) are linked with ASD. Because of these genetic changes, some people are more likely to have ASD. For example, families who have one child with ASD have an increased risk of having a second child with ASD. Similarly, if one twin is diagnosed with ASD, the other has a higher likelihood of having ASD.

However, genetics do not account for all ASD risk. Things in the environment may also contribute to ASD risk for some children. Researchers are examining whether environmental factors might interact with a person's genetic makeup to elevate ASD risk. The interaction between genes (made up of DNA within each cell in the body) and the environment is a major focus of the Study to Explore Early Development (SEED).

SEED is one of the largest studies designed to compare children with ASD and other developmental disabilities to children without these conditions. SEED has sites in California, Colorado, Georgia, Maryland, Missouri, North Carolina, Pennsylvania, and Wisconsin. Each SEED study site collects information on risk factors, including family members' health, experiences of mothers during pregnancy, and children's health and development during infancy and the first few years of life. In addition, SEED has collected blood and saliva, which give us genetic information about parents and children. Research using SEED's data will contribute to our understanding of how genetics and environmental factors contribute to the development of ASD.

Identifying the genetic causes of ASD can help us understand who may be at risk for ASD. This information can help doctors and caregivers diagnose ASD at earlier ages. Being able to diagnose ASD earlier allows children to begin ASD treatment at a younger age. Early treatment can help reduce how severe some ASD symptoms can be.

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Sharing Data on ASD: Opportunities for Research



Do you ever wonder if scientists around the country who study ASD pool their resources to better understand it? It turns out they do. Data, or information, collected from different ASD studies are combined on an ongoing basis into a database for researchers to access. By combining smaller studies into one database, scientists can have more information to study questions they couldn't look at before.

Q: How are scientists working together to study ASD?

A: Two big projects are underway that allow scientists to share data for research. Data from different projects are combined at a repository (a place where de-identified data are kept all together). The two big projects are called the National Database for Autism Research (NDAR) and the Database of Genotypes and Phenotypes (dbGaP). The data in NDAR and dbGaP are managed by the National Institutes of Health (NIH), which is part of the U.S. Department of Health and Human Services.

Q: What information is included in NDAR and dbGaP?

A: NDAR and dbGaP include information about study participants' genes, health, and health behaviors. Researchers can use this information to see if certain genes are linked with the risk of ASD as well as explore how genes and health factors combined might be related to autism.

To protect privacy, information that can be used to identify an individual person, such as names, addresses, birthdates, and other personal information, is not included in NDAR or dbGaP.

Q: Why are scientists sharing data this way?

A: By sharing data from smaller studies, researchers hope to learn about autism more quickly and at lower costs than they could if they worked separately. Sharing data also allows scientists to study genetics and ASD more easily.

Q: Will SEED share my data with NDAR or dbGaP?

A: SEED scientists have not yet sent information to NDAR or dbGaP. We will only share information for those families who gave us permission to do so.

Q: What information will SEED send to NDAR or dbGaP?

A: If permission is granted, SEED scientists will share genetic and other health data. We will not share any private information, such as names, addresses, birthdates, or phone numbers with NDAR or dbGaP.

Q: If my own or my child's data are sent to NDAR or dbGaP, will I get genetic results back?

A: No, genetic data are being used for research purposes only. We will not send the results of any genetic testing to families.

Q: Will I be asked for more specimens (such as blood, cheek brushes, or saliva) for NDAR or dbGaP?

A: No. Additional specimens are not needed if you participate in NDAR or dbGaP.

Q: Is there a risk that my child could be identified if his or her information is sent to NDAR or dbGaP?

A: Because everyone's genetic information is different, there is a very small chance that someone with access to the databases could trace an NDAR or dbGaP participant's genetic data back to the participant or biological relative. The risk of this happening is very small, as NIH has safeguards in place to protect participants' privacy.

Q: How do NDAR and dbGaP protect participants' privacy?

A: Only scientists approved by the NDAR Data Access Committee may obtain research data from NDAR. Scientists who have approval to analyze data must protect the data using standard procedures. Similarly, scientists who want to analyze data in dbGaP must get authorization from dbGaP's Data Access Committee.

Q: Can I change my mind about sharing my own or my child's information with NDAR or dbGaP?

A: If a participant decides later not to share his or her information with NDAR or dbGaP, he or she should contact the site where they enrolled to discuss next appropriate steps. Please note that information already shared with NDAR or dbGaP cannot be taken back because identifiers will be removed before sharing.

Q: How can I find out more about NDAR and dbGaP?

A: For more information on these projects, go to:

NDAR: <http://ndar.nih.gov/index.html>

dbGaP: <http://www.ncbi.nlm.nih.gov/gap>



Meet Colorado SEED

In Colorado, the University of Colorado School of Medicine (UCSOM), the Colorado School of Public Health (CSPH), and the Colorado Department of Public Health and Environment (CDPHE) work together to invite families to participate in the SEED study and to collect and analyze the data.

Situated in the Front Range of the Colorado Rockies, JFK Partners, on the University of Colorado Anschutz Medical Campus, houses the Colorado SEED. The Colorado SEED site is led by two professors:

- Cordelia Robinson Rosenberg, PhD, RN, a professor of pediatrics and psychiatry at UCSOM and
- Dr. Carolyn DiGuseppi, a professor of epidemiology at CSPH.

JFK Partners is designated as Colorado's University Center of Excellence in Developmental Disabilities (UCEDD) and Leadership Education in Neurodevelopmental Disabilities (LEND) Program. They have collaborative relationships with many organizations that are a part of Colorado's developmental disability and special healthcare needs communities.

By working together, UCSOM, CSPH, and CDPHE have also been able to conduct other multi-site CDC projects. One of these projects, which is led by CDPHE, is the Autism and Developmental Disabilities Monitoring (ADDM) Network. ADDM has the important task of monitoring the frequency of ASD in communities across the United States. In addition to the SEED and ADDM projects, several other research studies are ongoing at JFK Partners:

- Colorado Project LAUNCH (Linking Actions for Unmet Needs in Children's Health)
- SPARK (Simons Foundation Powering Autism Research for Knowledge)
- FORWARD (Fragile X Online Registration with Accessible Research Database)



Results Corner

Several SEED articles have recently been published. Below is a brief summary of two. Please see our website for a full listing of SEED publications. <https://ncseed.org/resources-for-parents/study-findings-2>

Family History of Immune Conditions and Autism Spectrum and Developmental Disorders: Findings from the Study to Explore Early Development

Croen, LA, Qian Y, Ashwood, P, Daniels JL, Fallin D, Schendel D, Schieve LA, Singer AB, Zerbo O

Autism Research, 2018

This study examined the relationship between autism spectrum disorder (ASD) and other developmental disorders (DDs) and having a family history of conditions related to immune system functioning. Such conditions include asthma, allergies, and autoimmune disorders such as eczema or psoriasis. Previous studies have suggested some association, but the results about specific conditions varied. SEED's large sample size and detailed data on specific types of immune disorders allowed researchers to conduct an in-depth analysis on this topic and examine the associations with ASD alongside associations with other DDs. The study findings show that maternal history of eczema or psoriasis and asthma are associated with both ASD and other DDs in children. Researchers also found that children with ASD are more likely to have eczema or psoriasis and allergies than children without ASD. Autoimmune disorders were not notably increased among children with other DDs. This study highlights the relationship between maternal health before and during pregnancy and ASD and other DDs, and provides researchers more information about the health of children with ASD.

Sleep Problems in 2- to 5-Year-Olds with Autism and Other Developmental Delays

Reynolds AM, Soke GN, Sabourin KR, Hepburn S, Katz T, Wiggins LD, Schieve LA, Levy SE

Pediatrics, 2019

This study assessed sleep problems, such as difficulties going to sleep or staying asleep through the night, in preschool-aged children with ASD, in comparison to children with other developmental disabilities (DDs) and children in the general population. SEED's large sample and detailed data on preschoolers allowed researchers to conduct a more in-depth analysis on this topic than in previous studies. Study findings show that children with ASD and children with other DDs who have some ASD symptoms have more sleep problems than children with DDs without ASD symptoms and children in the general population. Even when researchers used a conservative definition to classify children as having sleep problems, 47% of children with ASD and 57% of children with other DDs who had some ASD symptoms were reported to have sleep problems, compared to 29% of children with DDs but no ASD symptoms and 25% of children in the general population. Sleep is important for development in young children. Addressing sleep problems among children with ASD and children with other DDs who have ASD symptoms is an important component of healthcare needs in this population.



**Centers for Disease
Control and Prevention**
National Center on Birth Defects
and Developmental Disabilities

CADDRE

**Center for Autism and
Developmental Disabilities
Research and Epidemiology**



Highlights of SEED Progress

SEED 3 is growing!

The families joining SEED 3 are adding to the knowledge gathered in SEED 1 and SEED 2! More than 5,100 families finished the first two phases of the Study to Explore Early Development. The data from new families who finish SEED 3 will help us get a better idea of what puts children at risk of developing autism spectrum disorder.



Watch for future newsletters to see how SEED grows and visit www.cdc.gov/seed to see all the editions of the SEED newsletter.