N I C H D

National Institute of Child Health and Human Development

National Institutes of Health

Autism Research at the NICHD

U.S. Department of Health and Human Services
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Rett Syndrome

An important part of the mission of the National Institute of Child Health and Human Development (NICHD), part of the National Institutes of Health (NIH), within the U.S. Department of Health and Human Services, is to understand all stages of development throughout the lifespan—from birth and childhood, through adolescence and adulthood, and into old age.

One of the key areas of NICHD research is on *developmental disabilities*—problems that start in the developmental period (before age 3 years), and that cause delays or problems in the many skills that arise from infancy to adulthood.

Some of these disorders are well known, such as autism spectrum disorders (ASDs) and mental retardation. Others, such as Rett syndrome, are less common and, as a result, fewer people know about them.

The NICHD has been supporting research on Rett syndrome for more than two decades. Much is known about the disorder, its symptoms, and the lives of those families affected by it, but much remains unknown, too.

This fact sheet describes what we currently know about Rett syndrome: its causes, its symptoms, and its treatments. The fact sheet also explains some of the ongoing research supported by the NICHD to learn more about Rett syndrome and lists where families affected by Rett syndrome can go for more information and assistance.

NICHD researchers join parents, families, and communities affected by Rett syndrome in efforts to understand the disorder to better diagnose, treat, and maybe even prevent Rett syndrome.

What is Rett syndrome?

Rett syndrome[1] is a complex neurobiological disorder of development in which an infant seems to grow and develop normally at first, but then stops developing and even loses skills and abilities.

For instance, they stop talking, even though they used to say certain words. They lose their ability to walk properly, even though they used to walk normally. They stop using their hands to do things, even though they had already started to grab and point. They often develop **stereotyped** hand movements, such as wringing, clapping, or patting their hands. They stop responding to and interacting with others normally, even though they used to smile at others and follow them with their eyes.

Check the Glossary on pages 9-10 to learn how to say the **bolded** words and what they mean.

Until recently, researchers thought that Rett syndrome affected only females, but they now know that Rett syndrome affects a few males as well[2]. Because the number of males with Rett syndrome is very small, most of the statistics and research on Rett syndrome are specific to females. You will notice that this fact sheet refers mostly to females when talking about Rett syndrome.

Although many people with Rett syndrome live into their 40s and 50s, their lives are not easy. Many of them can't walk or talk, but can communicate with their eyes. Most need special education, diets, and treatments for their various problems.

Most people with Rett syndrome can't care for themselves and need someone to care for them throughout their lives.

What causes Rett syndrome?

For most females with Rett syndrome, the disorder results from a change in a single **gene**.

What are genes?

Genes are pieces of DNA, material that contains all the information needed to "build" a person. Genes are **hereditary,** meaning parents pass genes on to their children.

Most of this material is found in the **nucleus** of the cell, a storage area that keeps these materials together in one place. The nucleus stores the material in packages called **chromosomes**.

Most people have 46 chromosomes in most of their cells—23 from their mother and 23 from their father. Each chromosome is made up of different numbers of individual genes.

Genes contain the information your body uses to make **proteins**, the body's building blocks. Proteins make up the structure of your organs and tissues; your body needs them for chemical functions and interacting chemical pathways. Each protein performs a specific job in the body's different types of cells, and a single gene usually contains the information for making at least one protein.

The pattern, or sequence, of your genes is like a blueprint that tells your body how to build its different parts. For example, your genes control how tall you are, what color your hair and eyes are, and other features of your body and mind. Changes, or **mutations,** in that blueprint can cause changes in how your body or mind grows and develops.

How do genes cause Rett syndrome?

In 1999, NICHD-supported scientists[3] discovered that most girls with Rett syndrome have a change in the pattern of a single gene—the *Methyl-CpG-binding Protein 2 (MECP2) gene* on the X chromosome. Between 90 percent and 95 percent of girls with Rett syndrome have a mutation in this gene[4,5].

This gene makes methyl-CpG-binding protein 2 (MeCP2), which is necessary for the development of the nervous system—especially the brain. The mutation causes the gene to make less than the needed amounts of the protein, or to make a damaged protein that the body can't use. As a result, there may not be enough usable amount of the protein for the brain to develop normally.

Researchers are still trying to understand exactly how the brain uses MeCP2 and how problems with the protein cause the typical features of Rett syndrome. Normally, MeCP2 helps to "turn off" certain genes that make different proteins in nerve cells and other cells. Without MeCP2, the body keeps making these materials, even when it no longer needs them. After a while, having high amounts of these materials in the body may actually start to hurt the nervous system and cause the problems of Rett syndrome.

But, not all people with Rett syndrome have a genetic mutation. In 5 percent[4,6] of people with Rett syndrome, an *MECP2* mutation is not present or is not detectable. And, some people who have mutations on the *MECP2* gene don't show the typical features of Rett syndrome. Researchers are looking at different genes to see if they, too, can cause the symptoms of Rett syndrome.

If Rett syndrome is a genetic disorder, does that mean it is inherited?

In more than 99.9 percent[2] of cases of Rett syndrome, the genetic mutation is spontaneous, meaning that it occurs randomly. Random mutations are usually not inherited or passed from one generation to the next. In a very small percentage of families—about 1 percent[5]—Rett mutations are inherited and passed on by female carriers. Scientists are working to learn more about these families to understand how this inherited mutation arises.

How many people have Rett syndrome?

To date, researchers don't know exactly how many people have Rett syndrome. But, current estimates of the **prevalence** of Rett syndrome are that about one female out of 10,000[7] has the disorder.

What are the typical features of Rett syndrome?

Beginning between 3 months and 3 years of age, most children with Rett syndrome start to show some of the following symptoms:

- Loss of **purposeful hand movements**—They lose the ability to do things with their hands, such as grasping with fingers, reaching for things, or touching things on purpose.

- Loss of speech—Initially, they may stop saying words or phrases that they once said; later, they may make sounds, but do not say any purposeful words.

- Balance and coordination problems—These problems may start out as clumsiness and trouble walking. About 60 percent[8] of those with Rett syndrome are still able to walk later in life; others may become unable to sit up or walk or may become immobile.

- **Stereotypic movements**—One of the unique features of Rett syndrome is stereotypic hand movements—such as hand wringing—that can intensify and become almost continuous.

- Breathing problems—These problems may include **hyperventilation** and breath holding or **apnea**. These problems occur only while the person with Rett syndrome is awake, not during sleep.

- Anxiety and social-behavioral problems—These issues can range from not being comfortable in new places or situations, such as a mall, to autistic-like features, such as lack of eye contact.

- **Intellectual disability/mental retardation**—Intellectual disability is often significant. In fact, Rett syndrome is one of the leading causes of intellectual disability and autism in females.

During the last several years, researchers have described a broader set of features for Rett syndrome. Some people may be more or less affected by symptoms of Rett syndrome than others. Some people with Rett syndrome may still be able to say single words, while others are never able to talk. Some people with Rett syndrome are not able to sit up on their own and stay upright, while others have no problems with sitting.

Are there other problems associated with Rett syndrome?

A number of problems are common among those who have Rett syndrome. But having these other problems is not necessary to get a diagnosis of Rett syndrome. These problems can include:

- Approximately 80 percent[8] of girls with Rett syndrome have **scoliosis**. In some cases, the curving of the spine is so severe that the girls require surgery. For some, bracing relieves the problem, prevents it from getting worse, or delays or eliminates the need for surgery.

- **Seizures** are also a common problem[9] for those with Rett syndrome. Seizures may involve the whole body, or they may be staring spells with no movement.

- Many persons with Rett syndrome also have **constipation** and **gastro-esophageal reflux**. Gall bladder problems[10] may also occur and can range from **gallstones** to pain or discomfort in the abdomen.

- Some persons[11,12] with Rett syndrome have cardiac or heart problems, specifically problems with the rhythm of their hearts. For example, they may have abnormally long pauses between heart beats (as measured by an **electrocardiogram or ECG**), or they may experience other types of **arrhythmia.**

- Many girls[2] with Rett syndrome cannot feed themselves. Some have trouble swallowing, and others never develop the ability to chew food properly. In some cases, too, in spite of healthy appetites, girls with Rett syndrome do not gain weight or have trouble maintaining a healthy weight. As a result, some girls with Rett syndrome rely on **feeding tubes**.

- Problems with sleep, specifically disrupted sleep patterns at night (during childhood) and an increase in total and day time sleep (after age 5 years) are also common[13] among those with Rett syndrome. Some researchers[14] suggest that problems with sleep are among the earliest symptoms of Rett syndrome and can appear between 1 and 2 months of age.

What is the usual course of Rett syndrome?

As mentioned earlier, children with Rett syndrome seem to develop normally as infants, then regress or lose skills. Many persons with Rett syndrome also experience a period of stability.

Health care providers, relying on **consensus criteria**[15], view the onset of symptoms in four stages:

- Early Onset Phase—Development stalls or stops. Sometimes, the slowing or stopping is so subtle that parents and health care providers don't notice it at first.

- Rapid Destructive Phase—The child loses skills (regresses) quickly. Purposeful hand movements and speech are usually the first skills lost. Breathing problems and stereotypic hand movements usually also start during this stage.

- Plateau Phase—Regression slows, and other problems may seem to lessen or improve. Seizures and movement problems are common in the stage. Most people with Rett syndrome spend most of their lives in Stage 3.

- Late Motor Deterioration Phase—Individuals with Rett syndrome may become stiff or lose muscle tone; some become immobile. Scoliosis may be severe and require bracing or surgery. Stereotypic hand movements and breathing problems seem to lessen.

Researchers once thought that Stage 1 began around 6 months of age. But, after analyzing videotapes of Rett individuals taken from birth, they now know[16] that some infants with Rett syndrome only *seem* to develop normally. In fact, these infants show problems with very early development.

In one study[17], all of the infants with Rett syndrome showed problems with body movements from birth through age 6 months. Another 42 percent[17] showed stereotyped hand movements during this time period.

In light of these new findings, some health care providers feel that genetic screening for Rett syndrome is critical to ensure that these infants get help as early in life as possible. But, because genetic testing would miss 5 percent of infants with the disorder, clinical followup[18] is also critical to establish a diagnosis.

Is there a cure for Rett syndrome?

To date, there is no cure for Rett syndrome. But research[19] shows that early diagnosis of developmental disorders, such as Rett syndrome, is important for improving outcomes.

Interventions delivered early in life are more likely to result in positive effects on later skills and symptoms. The sooner treatment begins, the greater the opportunity for learning. Most people with Rett syndrome benefit from well-designed interventions, no matter what their age.

Are there treatments for Rett syndrome?

There are a variety of ways to help minimize the effects of Rett syndrome. Rather than addressing the syndrome as a whole, most treatments[20] try to reduce specific symptoms of Rett syndrome. These treatments generally aim to slow the loss of abilities, improve or preserve movement, and encourage communication and social contact.

People with Rett syndrome often benefit from a team approach to care, in which many different kinds of health care providers play a role along with family members. Members of this care team may include (but are not limited to):

- Physical therapists, who can help patients improve or maintain mobility and balance and reduce misshapen back and limbs

- Occupational therapists, who can help patients improve or maintain use of their hands and reduce stereotypic hand movements

- Speech-language therapists, who can help patients use non-verbal ways of communication and improve social interaction

Other members of the team may also include developmental specialists, developmental pediatricians, orthopedic surgeons, gastroenterologists, pulmonologists, cardiologists, neurologists, special education providers, and nurses. The involvement of family members is also critical to ensuring the well-being of those with Rett syndrome.

Other options, such as medication or surgery are also effective. For instance, surgery can correct scoliosis for some persons with Rett syndrome. Similarly, anti-seizure medications can effectively control seizures for many affected by Rett syndrome. Other medications can reduce breathing problems and can eliminate problems with heart beat rhythm.

Over-the-counter aids for indigestion and constipation can also help to reduce these problems. Calcium and mineral supplements may also help to strengthen bones, which slows the progress of the scoliosis.

If you have a question about treatments, talk to your health care provider, or consult one of the support organizations for Rett syndrome families listed in the *Where can I go for more information?* section of this fact sheet.

What are researchers doing to learn more about Rett syndrome?

The NICHD and other organizations continue their efforts to support research to understand Rett syndrome, in hopes of learning to slow, stop, and reverse its effects.

The 1999 finding of the *MECP2* gene was a big step forward and has provided many new avenues for research.

Some researchers[21] suggest that the specific type of mutation in the *MECP2* gene affects how mild or severe symptoms of Rett syndrome are. Studies are now underway to understand each mutation that may cause the features of Rett syndrome, and how these mutations might change the features of the syndrome. One NIH-funded study of the natural history of Rett syndrome should also provide new information about these topics.

Researchers are also trying to find other genes that may be involved in Rett syndrome. Some studies have helped to narrow the search for these genes, but much is still unknown about how these genes may cause or contribute to Rett syndrome.

Current findings[1] suggest that a **congenital** type of Rett-like syndrome, in which children have very severe seizures in early infancy, may involve the cyclin-dependent kinase-like 5 gene, *CDKL5*. But researchers still don't know how this gene might be involved, or what its protein product, cyclin-dependent kinase-like 5, specifically does in the brain. Studies on this and other genes are ongoing.

Other research focuses on understanding how **X chromosome inactivation (XCI)** affects people with Rett syndrome.

Cells randomly choose which X chromosome to use and which one not to use—called XCI. Because females have two X chromosomes, those with Rett syndrome usually have one mutated *MECP2* gene and one normal *MECP2* gene in most of their cells. But, only one X chromosome is active in each cell, and only the active chromosome makes proteins.

For some girls, then, XCI may mean that many cells use the normal chromosome, so they have higher levels of MeCP2 protein and milder features of Rett syndrome. In some females, only the normal chromosome is active, so these individuals are normal, even though they have a mutated gene.

Studies are also looking into XCI in males with Rett syndrome. For some males, the features of Rett syndrome sometimes occur with another genetic condition called **Klinefelter syndrome**. Most males have one X and one Y chromosome in most of their cells. But, males with Klinefelter syndrome have two X chromosomes and one Y chromosome, which means they may have one mutated *MECP2* gene and one normal *MECP2* gene.

In these cases, the normal gene may be able to make MeCP2, making the features of Rett syndrome less severe; or the mutated gene may cause the characteristic features of Rett syndrome.

In other males with Rett syndrome, not all the cells in the body have the mutated *MECP2* gene. In these cases, the cells are **mosaic**, meaning that they are different because some have the mutation and some do not. Efforts are ongoing to try and understand **mosaicism** and how it impacts the features of Rett syndrome.

With an understanding of how Rett syndrome affects the entire body, health care providers can better treat the problems associated with the syndrome. This knowledge is important not just for those affected by Rett syndrome, but also for any person touched by a developmental disorder.

Glossary

The Word or Phrase…	Is Pronounced…	And Means…
Arrhythmia	AY-rith-mee-uh	Any disorder of heart rate or heart rhythm. In some cases, the heart beats too fast, while in other cases, the heart beats too slow. But these are both situations of arrhythmia.
Apnea	APP-knee-ah	Periodic stop in breathing.
Chromosomes	kro-mu-SOM	One of the "packages" of genes and other DNA in the nucleus of a cell. Humans have 23 pairs of chromosomes, 46 in all. Each parent contributes one chromosome to each pair, so children get half of their chromosomes from their mothers and half from their fathers.
Congenital	kon-JENN-it-tull	Existing from birth; not hereditary or inherited.
Consensus criteria	konn-SENN-sus kry-TEER-ee-uh	A selected group of experts in a given field evaluate the available scientific information on a biomedical issue and develop a list of features, usually the minimum of those features, required for a specific diagnosis. In this case, a group of experts on Rett syndrome reviewed the available scientific information (including clinical trials, case histories, and journal articles) on the syndrome and compiled a list of those features a person must have to get a diagnosis of Rett syndrome.
Constipation	KONN-sti-pay-shun	Abnormal slowing or stoppage of bowel movements.
Electrocardio-gram (ECG)	ek-koe-CARD-dee-oh-gramm	A test that records and measures the electrical activity of the heart. Measures the rate and regularity of the heart beats, the presence of any damage to the heart, and the effects of drugs or devices used to regulate the heart beat.
Feeding Tube	FEED-ding TOOB	A small, soft, plastic tube placed directly into the stomach to provide feedings and medications.
Gallstones	GALL-stones	A deposit of cholesterol or other digestive product in the gall bladder.
Gastro-esophageal reflux	gass-TRO-ess-off-uh-jeel REE-flux	Flow of the stomach contents back into the esophagus; can result in heartburn and in esophageal damage.
Gene	JEEN	Pieces of DNA. They contain the information for making a specific protein.
Hereditary	ha-RED-ih-tare-ree	Something passed down by an ancestor, or from one generation to the next.
Hyperventilation	HIGH-purr-venn-till-lay-shun	Rapid breathing; excessive rate and depth of breaths that can cause a loss of carbon dioxide in the blood.

Glossary (Continued)

The Word or Phrase…	Is Pronounced…	And Means…
Intellectual disability/ Mental retardation	MENN-tul ree-tarr-DAY-shen	A term used when a person has certain limitations in mental functioning and in skills such as communicating, taking care of him or herself, and social skills.
Klinefelter syndrome	Kline-FELL-terr SINN-drome	Most males with Klinefelter syndrome are XXY—they have two copies of the X chromosome and one copy of the Y chromosome in each cell. These males may have low levels of the hormone testosterone beginning during puberty, which can lead to breast development, and an increased risk of breast cancer, reduced facial and body hair, and infertility. They may also have problems with speech and language development.
Mutation	my-TAH-shun	A permanent structural change in DNA. In most cases, DNA changes either have no effect or cause harm, but some mutations improve an organism's chance of surviving.
Mosaic	mo-SAY-ik	Cells that have different genotypes or genetic components.
Mosaicism	mo-SAY-i-si-zm	Having cells that are mosaic.
Nucleus	NOO-klee-us	The central cell structure that houses chromosomes.
Prevalence	prev-uh-lens	The number of people in a given population who have a certain condition or disease.
Proteins	PRO-teens	A large molecule made up of one or more chains of amino acids. Proteins perform a wide variety of activities in the cell and in the body.
Purposeful hand movements	PURR-puss-full HAND MOOV-ments	Moving and controlling the hands to do something, such as grab an object or touch something.
Scoliosis	Skoe-lee-OH-siss	Curving of the spine.
Seizures	SEE-jurs	A sudden attack, often one of convulsions, as in epilepsy. Seizures don't necessarily involve movement or thrashing; they can also make someone seem as though they are frozen, unmoving.
Stereotyped behaviors	STARE-ee-oh-tipd	An action that is repeated without change.
Susceptibility	suss-ept-ih-BILL-it-tee	The state of being predisposed to, sensitive to, or of lacking ability to resist manifestations of something (such as a pathogen, familial disease, or drug); a person who is susceptible is more likely to show symptoms of a disorder.
X-chromosome inactivation	EKS-kro-ma-SOM inn-ak-tih-VAY-shun	In females, the phenomenon by which one X chromosome is randomly inactivated in early embryonic cells; all descendant cells, then, also have that chromosome inactive.

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Where can I go for more information about Rett syndrome?

For more information about Rett syndrome and other developmental disabilities, contact the NICHD. The NICHD supports and conducts research on topics related to the health of children, adults, families, and populations, including Rett syndrome and other developmental disabilities. The mission of the NICHD is to ensure that every person is born healthy and wanted, that women suffer no harmful effects from the reproductive process, and that all children have the chance to fulfill their full potential for a healthy and productive life, free of disease or disability, and to ensure the health, productivity, independence, and well-being of all people through optimal rehabilitation.

You can contact the NICHD through the **NICHD Information Resource Center** at:

Phone: 1-800-370-2943 (TTY: 1-888-320-6942)
Fax: (301) 984-1473
Mail: P.O. Box 3006, Rockville, MD 20847
E-mail: NICHDInformationResourceCenter@mail.nih.gov (Please use AUTISM in the subject line)
Internet: http://www.nichd.nih.gov/autism

The National Library of Medicine also provides information on Rett syndrome through *Genetics Home Reference* at http://ghr.nlm.nih.gov/condition=rettsyndrome. . The Web site also provides links to support organizations for families affected by Rett syndrome at http://ghr.nlm.nih.gov/condition=rettsyndrome/show/Patient+support.

The NIH Web site also has information about Rett syndrome at http://health.nih.gov/result.asp/1037.

These organizations also provide information about Rett syndrome to families and patients:

- International Rett Syndrome Association

  Phone: 1-800-818-RETT
  Mail: 9121 Piscataway Road, #2B
  Clinton, MD 20735
  E-mail: admin@rettsyndrome.org
  Internet: http://www.rettsyndrome.org

- Rett Syndrome Research Foundation

  Phone: (513) 874-3020
  Mail: 4600 Devitt Drive
  Cincinnati, OH 45246
  Internet: http://www.rsrf.org

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