

Family Planning for Patients with Spinocerebellar Ataxia (SCA)



SCAs fall under the larger diagnosis of ataxia. An SCA diagnosis is confirmed through genetic testing to look for the related gene change. People with SCA have a 50% chance of passing the condition on to each of their children.

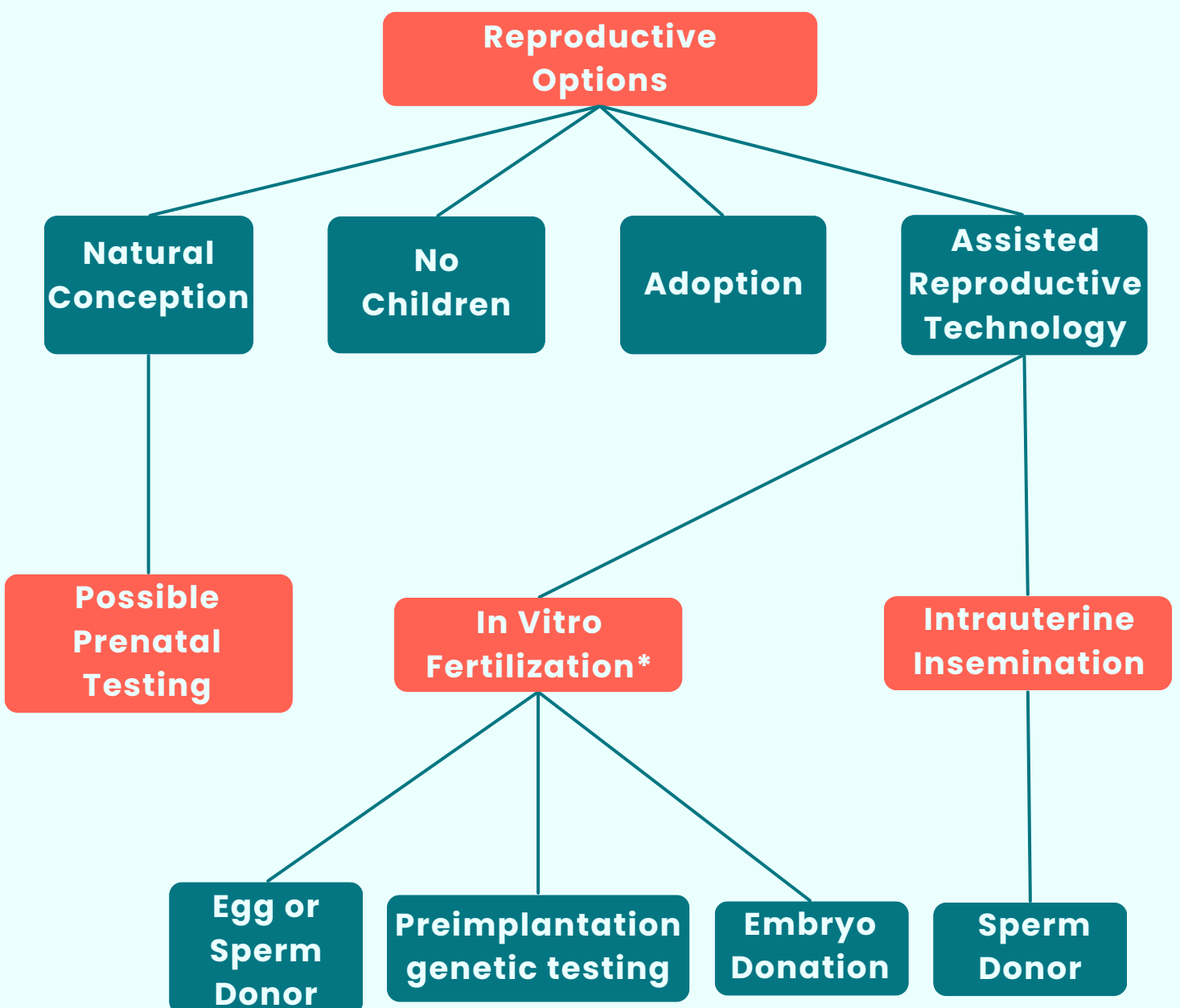
For some SCAs, there is a risk of "genetic anticipation." This means that as the condition is passed through the family, it can start at an earlier age and/or be more severe than others in the family.

Pregnancy Concerns and Considerations

There are some things to keep in mind when planning a pregnancy if someone has SCA. In addition to common side effects of pregnancy such as feeling more tired and needing to use the bathroom more often, some people will notice changes in their disease during pregnancy. The most common changes are more trouble with speech, balance, and coordination. These changes are typically temporary and will go away after pregnancy. These symptoms should be monitored by a neurologist or trained healthcare provider.

Reproductive Options

This chart shows different family planning options that people with SCA can consider. The next few pages will explain each option in detail.



***All options under in vitro fertilization have the option to use surrogacy.**

No Children: Some people with a chance of passing SCA on to their children choose to not have children.

Natural conception: Some people with a chance of passing SCA on to their children choose to get pregnant naturally without using any of the methods below before or during pregnancy. Others choose to use one of the methods below before or during pregnancy.

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Prenatal Testing: During pregnancy, doctors can test the fetus for SCA. These tests are called "amniocentesis" and "chorionic villus sampling (CVS)." They involve taking a sample of the placenta or amniotic fluid (the fluid that surrounds the baby). A genetic test is done on the sample to see if the fetus has SCA or not. This test is usually covered by insurance.

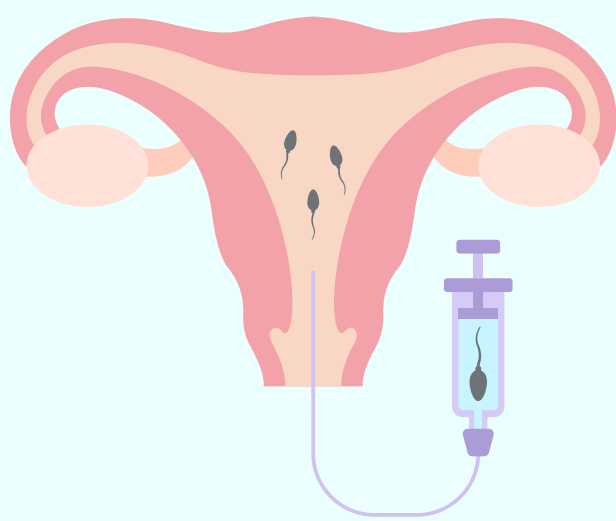


Some people might use this information to prepare for a child with the condition. Others might decide to end a pregnancy if the fetus has the condition.

There is a 1 in 200 to 1 in 500 risk of miscarriage after doing prenatal testing.



These tests can be done starting as early as 11 weeks of pregnancy.

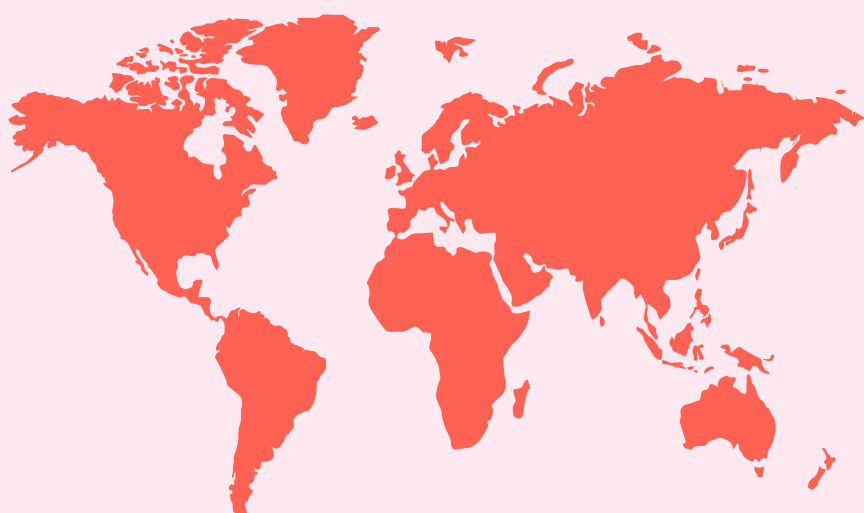


Intrauterine Insemination (IUI): IUI is a procedure where sperm is put directly into the uterus. If the person providing sperm to the pregnancy has SCA, a sperm donor can be used via IUI to avoid the risk of passing SCA on to the child. Medication is often given to the female patient to help them release an egg at the time the sperm is put in the uterus. IUI is typically a quick procedure and is done without anesthesia. As IUI can use a sperm donor, it is useful in avoiding passing SCA on to a child if the sperm provider to the pregnancy has SCA. It is not useful if the person providing an egg to the pregnancy has SCA.

IUI costs between \$150 and \$400. The cost of using a sperm donor ranges from a few hundred to a few thousand dollars depending on the sperm bank.



Adoption: Adoption is legally becoming the parent of a child who is not biologically related to you. The child can be any age.



There are several ways to adopt, such as through a private agency or lawyer, independently, or through the state (adopting through foster care). Adoption can also be domestic or international. Laws differ by location.

Adoptive parents usually must complete interviews, background checks, and a home study. Adoption can take several years to complete. For international adoption, there may be additional steps including documentation, immigration policies, and travel.



The cost of adoption can vary from almost nothing to tens of thousands of dollars. Private adoption agencies tend to be more expensive than public state adoption. For adoption from foster care, there are usually no application fees and there may be adoption tax credits available.

The next several options use in vitro fertilization (IVF).

IVF: In IVF, a fertility medication is used to help multiple eggs mature in a patient's ovaries. These mature eggs are taken out of the ovaries while a patient is under anesthesia. The eggs are fertilized by sperm in a lab. The fertilized eggs grow into embryos and 1-2 are then transferred into a patient's uterus. Completing all of these steps once is called a "cycle." This process can be done using the reproductive couple's own egg and sperm or may involve using a donor.



One cycle of IVF takes 2-3 months and costs between \$10,000 and \$30,000. More than 1 cycle may be needed to have a successful pregnancy. If there are leftover embryos from a previous cycle, only the transfer step may be needed. A transfer alone costs around \$5,000. Insurance coverage varies and many insurance plans do not provide coverage. Sometimes, IVF will make more embryos than someone needs. These parents are left with the question of what to do with the leftover embryos.



Egg or sperm donor: If the person providing an egg or sperm to the pregnancy has SCA, a donor can be used with IVF. This avoids the person with SCA passing the condition on to their child. Donor sperm and donor eggs can be bought from fertility clinics, sperm/egg banks, or private agencies.



Donors typically undergo genetic screening, a thorough medical history, and a physical exam. The cost to use a sperm donor is typically between \$300 and \$4,000. The cost to use an egg donor is typically between \$5,000 and \$20,000.

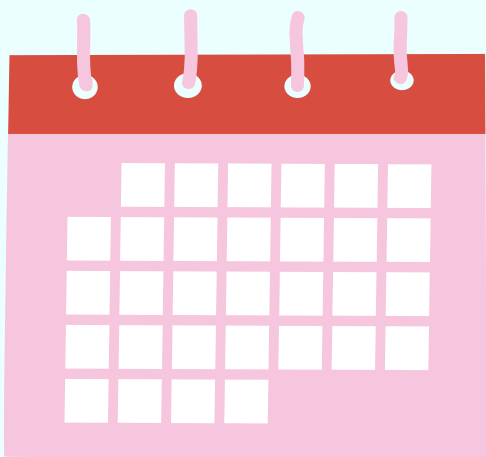
Surrogacy: After an embryo has been created using IVF, the embryo can be put into any person's uterus. If it is put into the uterus of a person not intending to parent the child, it is called gestational carrier surrogacy. Typically, the gestational carrier (surrogate) will not be related to the baby they are carrying. This may be done to avoid the person with SCA carrying the pregnancy.





Preimplantation genetic testing (PGT-M): Embryos created during IVF can be genetically tested for SCA using PGT-M. This is done before transfer to the uterus. Then, only embryos that do not carry the gene change that causes SCA are transferred to the uterus.

The child is biologically related to both parents. In some cases, all the embryos may have the gene change associated with SCA, and so none may be chosen for transfer. These parents are left with the question of what to do with these affected embryos.



Not every couple will be able to use PGT-M. Typically, samples from both members of the reproductive couple and other relatives are needed. The process requires developing a specific test, called a probe. This can take an extra 2-4 months before starting IVF.

The price of PGT-M alone is between \$5,000 and \$10,000. This is usually not covered by insurance. This cost does not include the cost of IVF or surrogacy if it is being used.



Embryo Donation: During IVF, some people will make more embryos than they need. These extra embryos may be saved for use in a later cycle. Some people will choose to donate their extra embryos after they complete their family. In this case, most often, the embryo will not be related to the recipients. The cost to use and complete the transfer step of IVF with donated embryos is around \$2,500 to \$5,000.

Resources for Patients

- **North American Counsel on Adoptable Children:** <https://nacac.org>
 - Advocacy group for policies and practices that support adoptive families
 - Provides information and resources to prospective adopters and adoptive parents including how to adopt, adoption support services, and adoption assistance benefits
- **Resolve:** www.resolve.org
 - Local support groups and family building professionals (reproductive endocrinologists, infertility specialists, urologists, and therapists)
 - Helpline 866-668-2566: request support on any topic, and a Resolve volunteer will call you back within 1-3 days
- **Fertility IQ:** <https://www.fertilityiq.com>
 - Provides online courses for topics including IVF, IUI, embryo transfer, surrogacy, adoption, budgeting, and more.
 - Also provides a list of patient-validated doctors and clinics across the United States
- **Society for Assisted Reproductive Technology (SART):** www.sart.org
 - Patient-friendly information about all types of assisted reproductive technology, success rates, medications, protocols, etc.
 - Statistics from SART member clinics