



the
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Consortium



Center for Reproductive Health After Disease

Fertility Preservation Fact Sheet

Adrenoleukodystrophy (ALD)

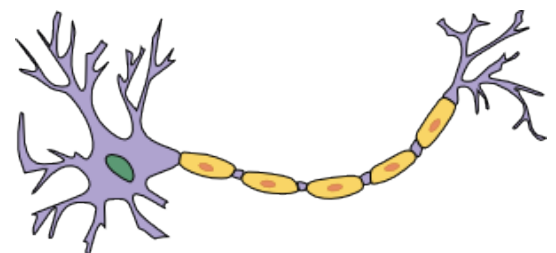
5 Questions to Ask Your Child's Health Care Provider

1. How is ALD affecting my child's health right now?
2. How quickly does my child need to start treatment?
3. Will treatment harm my child's future fertility?
4. What fertility options are out there?
5. Can my child have children in the future?

What is Adrenoleukodystrophy (ALD)?

Adrenoleukodystrophy (ALD) is a rare genetic condition that causes neurological deficits in males. ALD is caused by a gene mutation, or a misspelling in the body's instructions. The mutation stops the body from breaking down very-long-chain fatty acids (VLCFAs). VLCFAs come from our food and our body breaks them down for energy. Males with ALD can't break down the VLCFAs and they build-up in the nervous system, adrenal gland, and testis.

The cerebral form of ALD becomes symptomatic in childhood and the first features of ALD are often misdiagnosed as Attention Deficit Hyperactivity Disorder (ADHD). ALD causes cognitive deficits, including: poor handwriting, impaired memory, poor attention and reasoning, and difficulties with hearing and vision. As the disease progresses, children begin to have trouble moving muscles, trouble identifying objects by touch, "word deafness", weakness on one side of the body, seizures, and adrenal insufficiency.



The Center for Reproductive Health After Disease: Adrenoleukodystrophy (ALD)

Why is Fertility at risk in ALD?

Boys diagnosed with ALD are strongly recommended to have hematopoietic stem cell transplantation (HSCT) as early as possible. HSCT slowly provides the body with a new set of cells that can break down VLCFAs—leading to possible disease stabilization and reversal of the neurological changes seen in childhood ALD. Before a child can have HSCT, they may have to have total body irradiation (TBI) and conditioning medication to prepare their body for the transplant. Both TBI and the necessary conditioning medications, like chemotherapy, are considered *gonadotoxic*. Gonadotoxic medications cause *azoospermia*.

What is Azoospermia?

Azoospermia is the medical term used to describe a defect in how the body creates sperm. It causes ejaculation of semen that does not contain sperm and results in infertility.

Fertility Preservation Options

HSCT has a high risk of azoospermia, therefore fertility preservation options should be discussed with all young men of reproductive age and parents of children needing HSCT.

Boys with ALD need HSCT as early as possible and have usually not gone through puberty at this time. Because pre-pubertal boys cannot produce semen, the only option available to preserve fertility is *testicular tissue cryopreservation*. Testicular tissue cryopreservation involves a biopsy to remove testicular tissue, which contains cells that create sperm and sperm itself. The tissue is frozen until the male wishes to start

a family. At that time *intracytoplasmic sperm injection* (ICSI) can be used to achieve fertilization. ICSI is when a single sperm is microinjected directly into an egg.

Future Directions in Fertility Preservation

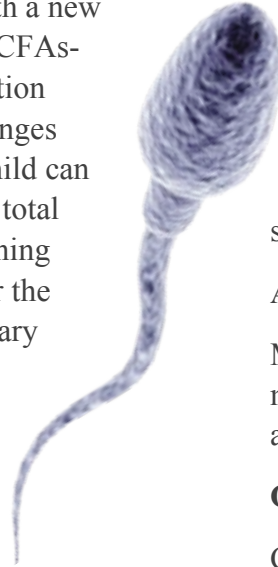
Current research may make it possible in the future to thaw testicular tissue that has been cryopreserved and transplant it back to the testes to result in possible natural creation of sperm within the body.

Alternative Options

Males with ALD who survive into adulthood may choose to use donor sperm or consider adoption when family planning.

Questions?

Call the 24-hour FERTLINE to ask your fertility preservation questions, get connected with a fertility preservation program near you, and access resources, tools, and support!



FERTLINE
866-708-FERT (3378)

Online Resources

<http://oncofertility.northwestern.edu>

<http://www.myoncofertility.org>

<http://www.savemyfertility.org>

Information found here or elsewhere on the oncofertility.northwestern.edu website should not be considered medical advice, diagnosis, or treatment. Any information on this document or website should not be used in lieu of consultation with your healthcare provider or physician. Before starting any course of treatment, always consult a qualified health care provider. Do not delay seeking or disregard medical advice because of anything you have read or seen here. For information regarding fertility options contact the FERT line at 866-708-FERT (3378).