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Werner Syndrome [1]

What is Werner syndrome?

Werner syndrome, also called progeria, is a hereditary condition associated with premature aging and an increased risk of cancer and other diseases. Signs of Werner syndrome usually develop in the teenage years. A person with Werner syndrome does not have the usual growth spurt typical of a teenager and tends to be shorter than others. Signs of aging, including wrinkles, gray hair and hair loss, may appear in their 20s. In their 30's, cataracts or clouding of the eye's lens, type 2 diabetes, skin ulcers, a beaked nose, cancers, and osteoporosis, meaning decrease in bone mineral density, may develop. One of the most significant health problems faced by people with Werner syndrome is the early development of atherosclerosis, commonly known as hardening of the arteries, which can lead to a heart attack.

What causes Werner syndrome?

Werner syndrome is a genetic condition. This means that the risk of Werner syndrome can be passed from generation to generation in a family. Mutations (alterations) in the *WRN* gene are known to cause Werner syndrome. Research is ongoing to learn more about Werner syndrome.

How is Werner syndrome inherited?

Normally, every cell has two copies of each gene: one inherited from the mother and one inherited from the father. Werner syndrome follows an autosomal recessive inheritance pattern, which means that a mutation must be present in both copies of the gene for a person to be affected. This means that both parents must pass on a gene mutation for a child to be affected. A person who has only one copy of the gene mutation is called a carrier. When both parents are carriers of a recessive gene mutation, there is a 25% chance that a child will inherit two mutations and be affected.

Options exist for couples interested in having a child when they know that one of them carries a gene mutation that increases the risk for this hereditary cancer syndrome. Preimplantation genetic diagnosis (PGD) is a medical procedure done in conjunction with in-vitro fertilization (IVF). It allows people who carry a specific known genetic mutation to have children who do not carry the mutation. A woman's eggs are removed and fertilized in a laboratory. When the embryos reach a certain size, one cell is removed and is tested for the hereditary condition in question. The parents can then choose to transfer embryos that do not have the mutation. PGD has been in use for over a decade, and more recently has been used for several hereditary cancer predisposition syndromes. However, this is a complex procedure with financial, physical, and emotional factors for couples to consider before starting. For more information, talk with an assisted reproduction specialist at a fertility clinic.

How common is Werner syndrome?

Werner syndrome is considered to be very rare. It is estimated that one in 200,000 people in the United States may have Werner syndrome. Werner syndrome is somewhat more common in Japan and Sardinia, where it is estimated that one in 30,000 people may have the condition. This is because a genetic mutation was known to occur many generations ago, when their population was smaller in number, and over time the mutation has been passed down repeatedly, affecting a higher number of people; this is called a founder mutation.

How is Werner syndrome diagnosed?

Currently, the diagnosis of Werner syndrome is suspected if someone has several of the features listed below.

Common features of Werner syndrome (diagnosed after age 10):

- Cataracts in both eyes
- Skin changes associated with aging
- Characteristic facial features, including wrinkling and loss of muscle tone
- Short stature (height)
- Early graying or thinning of the hair
- Family history of Werner syndrome
- Positive 24-hour urine hyaluronic acid test

Other features seen in Werner syndrome:

- Type 2 diabetes
- Decreased fertility
- Osteoporosis
- Cancer
- Bone changes in the fingers and toes
- Tissue changes

- Early atherosclerosis, meaning plaque buildup in arteries
- Hoarse or high-pitched voice
- Flat feet

Guidelines for the diagnosis of Werner syndrome have been proposed but may change over time as more is learned about this condition. Genetic testing for mutations in the *WRN* gene is only available as part of research studies (clinical trials). Mutations in the *WRN* gene are found in about 90% of people with Werner syndrome.

What are the estimated cancer risks associated with Werner syndrome?

The risk of cancer is increased in people who have Werner syndrome, but the specific risk of cancer is unknown. Types of cancers reported in people with Werner syndrome include [thyroid cancer](#) [2], [melanoma](#) [3], [soft tissue sarcoma](#) [4], and [osteosarcoma](#) [5] (bone cancer).

What are the screening options for Werner syndrome?

Suggested screenings for people diagnosed with Werner syndrome include:

- Yearly screening for type 2 diabetes
- Yearly lipid profile (blood test)
- Yearly eye examination to look for signs of cataracts
- Yearly physical and dermatological (skin) examinations to screen for cancers associated with Werner syndrome

People with Werner syndrome should also avoid smoking, be physically active, and maintain a healthy weight to help decrease the risk of heart disease. Any chest pains, also known as angina, should be carefully evaluated by a doctor. Due to the risk of skin cancer, people with Werner syndrome should also limit sun exposure and [use skin protection when outside](#) [6].

Screening recommendations may change over time as new technologies are developed and more is learned about Werner syndrome. It is important to talk with your doctor about appropriate screening tests.

Find out more about [what to expect when having common tests, procedures, and scans](#) [7].

Questions to ask the doctor

If you are concerned about your risk of cancer, talk with your doctor. Consider asking the following questions:

- What is my risk of cancer?
- What can I do to reduce my risk of cancer?
- What are my options for cancer screening?

If you are concerned about your family history and think you or other family members may have Werner syndrome, consider asking the following questions:

- Does my family history increase my risk of cancer?
- Does it suggest the need for a cancer risk assessment?
- Will you refer me to a genetic counselor or other genetics specialist?
- Should I consider [genetic testing](#) [8]?

More Information

[The Genetics of Cancer](#) [9]

[Genetic Testing](#) [8]

[What to Expect When You Meet With a Genetic Counselor](#) [10]

[Collecting Your Family Cancer History](#) [11]

[Sharing Genetic Test Results with Your Family](#) [12]

Additional Resources

National Cancer Institute

www.cancer.gov [13]

American Cancer Society

www.cancer.org [14]

CancerCare

www.cancercare.org [15]

To find a genetic counselor in your area, ask your doctor or visit these websites:

National Society of Genetic Counselors

www.nsgc.org [16]

National Cancer Institute: Cancer Genetics Services Directory

www.cancer.gov/cancertopics/genetics/directory [17]

Links

[1] <http://www.cancer.net/cancer-types/werner-syndrome>

[2] <http://www.cancer.net/node/31262>

[3] <http://www.cancer.net/node/31265>

[4] <http://www.cancer.net/node/31379>

[5] <http://www.cancer.net/node/31389>

- [6] <http://www.cancer.net/node/24659>
- [7] <http://www.cancer.net/node/24959>
- [8] <http://www.cancer.net/node/24895>
- [9] <http://www.cancer.net/node/24897>
- [10] <http://www.cancer.net/node/24907>
- [11] <http://www.cancer.net/node/30761>
- [12] <http://www.cancer.net/node/24906>
- [13] <http://www.cancer.gov/>
- [14] <http://www.cancer.org/>
- [15] <http://www.cancercare.org/>
- [16] <http://www.nsgc.org/>
- [17] <http://www.cancer.gov/cancertopics/genetics/directory>