



Intellectual Developmental Disorder and Retinitis Pigmentosa

Other names: IDDRP **Gene involved:** *SCAPER*

What is IDDRP?

IDDRP is an inherited condition affecting the brain and eyesight. Children are born with IDDRP and do not grow out of it. Sometimes, families will have more than one child with IDDRP.

Children around the world have IDDRP. Speech delay, learning difficulties, and vision problems come from spelling changes in a genetic instruction called SCAPER.

What are the early signs and symptoms?

Babies with IDDRP can have similar development to their unaffected siblings but may show mild delays. The heart, lungs, kidneys, and liver are normal, so babies are generally healthy.

What Happens as Children Get Older?

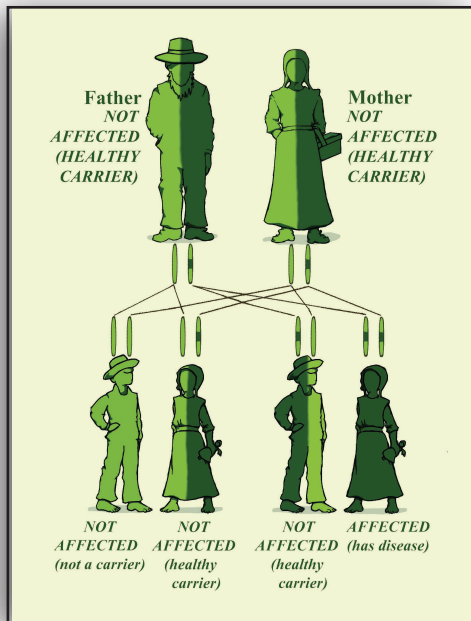
- Infants can be slower in learning to walk than their siblings
- Children can be slower in learning to talk
- Hyperactivity and mild learning disabilities are common
- Children can develop loss of night vision as early as age 10. This can progress to problems with daytime vision.

Management

There is no cure for IDDRP, but affected children thrive in loving homes and communities. Infants and toddlers can learn to walk and talk faster with speech, occupational and physical therapy. Children with learning delays do well in supportive schools. Sometimes, hyperactivity can be treated with medication. Vision should be checked yearly with the appropriate eye specialist.

Diagnosis

A gene test is required to make the diagnosis. To arrange this, please see the contact information below.



Lily Stoltzius

Autosomal Recessive Inheritance

Genes are instructions for growth and development. We have two copies of each gene. One copy is inherited from our mother, and one copy is inherited from our father. Children with IDDRP have a spelling change in BOTH copies of their *SCAPER* genes. This means they have no working copy of the *SCAPER* instruction.

People with one normal copy of the *SCAPER* gene and one misspelled copy are called "healthy carriers".

When two healthy carrier parents have a child, there is a:

- 1 in 4 chance the child will have IDDRP, a
- 1 in 2 chance they will be a healthy carrier
- 1 in 4 chance they will inherit two normal copies of the *SCAPER* gene and be neither affected nor be a carrier

This informational pamphlet is a project of New Leaf Center - a member of the Plain Community Health Consortium (PCHC)



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Center for Special Children (La Farge, WI) **608-625-4039**
Central Pennsylvania Clinic (Belleville, PA) **717-935-2065**
Clinic for Special Children (Strasburg, PA) **717-687-9407**
DDC Clinic (Middlefield, OH) **440-632-1668**
Midwest Genetics Network (Okemos, MI) **517-324-8300**
The Community Health Clinic (Topeka, IN) **260-593-0108**
UPMC Children's Hospital of Pittsburgh (Pittsburgh, PA) **412-692-5070**
WeCare Clinic - Medical Care for Special Needs (Pembroke, KY) **270-962-7383**