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**HELP US GET
REFSUM PATIENTS
DIAGNOSED
EARLIER, IMPROVE
QUALITY OF LIFE
AND FIND A CURE!**

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Global DARE Foundation is a registered non-profit public charity.

Our mission is to promote world-wide awareness and better quality of life for all who are diagnosed with Adult Refsum Disease.

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CONTACT / DONATE

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***We DARE to believe in a
cure for Refsum Disease***

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REFSUM DISEASE

Adult Refsum disease is a genetic disorder that impacts the metabolism of phytanic acid.

It is one of the few causes of Retinitis Pigmentosa that has a **proven dietary therapy to slow vision and hearing loss.**



**DefeatAdult
RefsumEverywhere.org**

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CURRENT THERAPIES

Low Phytanic Acid Diet

A strict diet low in phytanic acid is used for long-term management. This diet includes the exclusion of foods that are high in phytanic acid such as dairy products, beef, lamb and some fish.

Plasmapheresis

A dialysis-type process that is the direct removal of phytanic acid in the blood. Typically used in acute management and occasionally used for long term management.

Symptom Management

Symptom management could include cataract surgery, eye drops, hearing aids, cochlear implants, skin lotions, pain management, knee replacement, heart and liver transplant.

CLINICAL FEATURES OF REFSUM DISEASE



Retinitis
Pigmentosa
(loss of vision)



Loss
of Smell



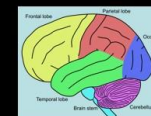
Peripheral
Neuropathy
(numbness,
nerve pain)



Loss of
Hearing



Bone
Abnormalities



Cerebellar
Ataxia
(balance issues)



Ichthyosis
(itchy, scaly
skin)

Other Symptoms include: cataracts, nystagmus, small pupils, skeletal dysplasia, cardiac arrhythmia, weakness

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PATIENT REGISTRY

A patient registry will bring the Refsum community and researchers together to gain a better understanding of Refsum Disease and drive better therapies.

ENROLL TODAY at the [Global DARE Foundation website](#).

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DIAGNOSIS

Diagnosis of Refsum Disease can be done through the following:

- Clinical exam
- Phytanic Acid Level
- Fibroblast Test
- Genetic Testing

Additional information and videos are available at the [Global DARE Foundation website](#)