HOW DO I KNOW IF I AM A CARRIER?

You can find out if you are a carrier by a blood test. Your partner should also have this test. If you choose to have this test, we will give you more information and support you throughout the process. Prenatal diagnosis (testing the baby during the pregnancy) is also available.

Eeyou Awaash Foundation
ᐄᔨᔨᐅᐊᐧᐋᔑᔥ ᐌᐅᓐᑌᔑᓐ

THIS PROGRAM WAS DEVELOPED IN COLLABORATION WITH THE EEYOU AWAASH FOUNDATION (EAF)

A foundation of parents and grandparents who lost children to CLE and CE.

FOR MORE INFORMATION, PLEASE CONTACT:

Educational and Carrier Screening Program for CE-CLE at your local CMC (Awash Program)

creehealth.org/services/ce-cle

CE-CLE SCREENING PROGRAM

CONSEIL CRI DE LA SANTÉ ET DES SERVICES SOCIAUX DE LA BAIE JAMES
CREE BOARD OF HEALTH AND SOCIAL SERVICES OF JAMES BAY

CHU Sainte-Justine
Le centre hospitalier universitaire mère-enfant
Université de Montréal

Eeyou Awaash Foundation
ᐄᔨᔨᐅᐊᐧᐋᔑᔥ ᐌᐅᓐᑌᔑᓐ

EDUCATIONAL & CARRIER SCREENING PROGRAM FOR CE-CLE

WHAT ARE CLE and CE?
CLE = CREE LEUKOENCEPHALOPATHY
CE = CREE ENCEPHALITIS

Both of these diseases affect the brain development of young children.

CLE and CE are hereditary diseases.

Hereditary means that the diseases are passed from parent to child.

CLE
(CREE LEUKOENCEPHALOPATHY)

- Babies with CLE look healthy at birth.
- The first signs start 3 to 9 months after birth.
- These signs usually start after a fever or virus.
  - The baby may have convulsions (seizures).
  - Muscles may become weak, or too stiff (spastic).
  - Muscle and eye movements and positions may be abnormal.

Babies usually die after a few weeks or months.

CE
(CREE ENCEPHALITIS)

- Babies with CE usually have problems from birth.
  - They have small heads, and weak muscles.
  - They have slow physical and mental development.
  - They may be unable to sit, walk or speak.
  - They are often blind, and have very stiff (spactic) muscles.
  - They suffer from many infections.

Children with CE usually die in early childhood.

CLE — Death usually occurs within the first year

CE — Death usually occurs at a young age (3 months to 17 years)

THERE IS NO CURE FOR EITHER DISEASE

Treatment can help symptoms and improve comfort.

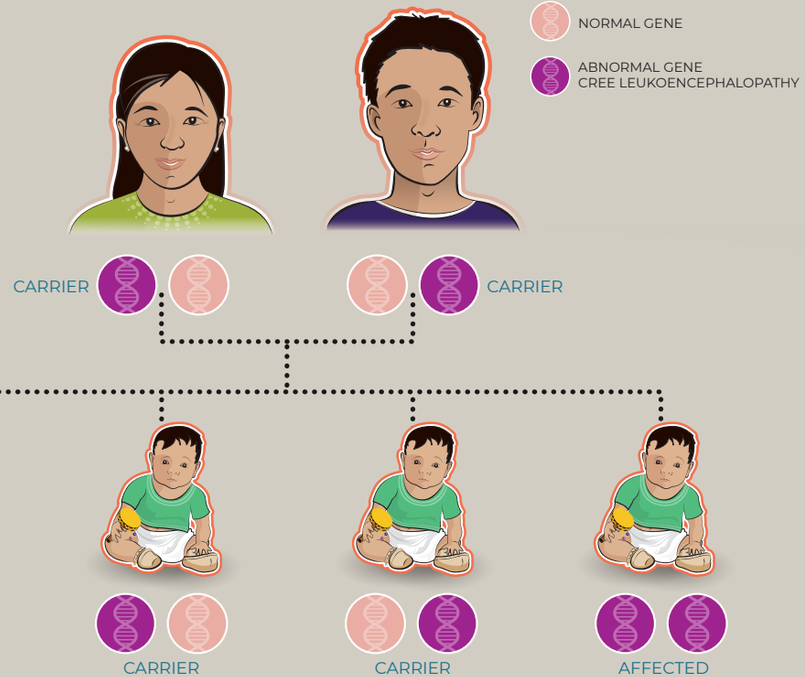
HOW COMMON ARE THESE DISEASES?

1 in 300-400 children can be affected in Eeyou Istchee.

- 1 in 11 people are carriers of CLE
- 1 in 17 are carriers of CE

IF MY PARTNER AND I ARE HEALTHY, HOW CAN WE HAVE A CHILD WITH THE DISEASE?

- Each person has 2 copies of every gene, 1 from the mother and 1 from the father.
- A gene is like an instruction manual that tells the body how to grow and work.
- Children with CLE or CE have two unhealthy (defective) genes.
- People with only one defective gene are completely healthy. But since they carry one defective gene, they are called carriers.



1 **If you and your partner are both carriers, it means that there is a:**

- 75% chance that the baby will not be affected by CLE or CE for each pregnancy.
- 50% chance that the child will be healthy, but will carry the disease gene.
- 25% chance that the child will have CLE or CE disease
- 25% chance that the child will be healthy, and will not be a carrier..

2 **If only one of you is a carrier, there is NO chance** that your child can have the disease. However, your child may be a carrier.

3 **If neither you nor your partner is a carrier**, all your children will be healthy and none will carry the disease gene.