

# What do high school students remember about the CE-CLE Carrier Screening Program?

## What is the

### CE-CLE Carrier Screening Program?

It is a program created in 2006 thanks to the efforts of the Eeyou Awaash Foundation and the Cree Health Board. The purpose of the program is to raise awareness in Cree communities about CE and CLE.



## What is CE and CLE?

CE and CLE are diseases that make babies and toddlers very sick because their **brain** does not work well.

These diseases are **genetic**--some people "carry" them in their genes. If they do, there is some chance they will pass on the disease to their baby.



## How can we find out if someone has a chance of having a baby with CE or CLE?

A **blood test** can tell people if they carry these genes. The program offers the blood test to anyone who wants to see if they carry the genes. We are now doing the evaluation of the program to see how it is working.

## How does the program work in high schools?

Every year, the program nurse visits all Secondary 3-5 high school students in Eeyou Istchee to give them a presentation on CE and CLE. After, she meets the students individually to ask them if they have questions and if they want to do the blood test. If they do, she takes their blood in school. If not, she asks them again the next year during her school visit.

The blood test is not mandatory; it is a choice.

## How are we checking how the program is doing?

The Program teamed up with Researchers from Sainte-Justine's Hospital who are providing the expertise to develop and carry out the evaluation.

We asked high school students from Secondary 3-5 to answer 3 surveys:



**Survey A:** Right before the education session given by the program nurse (first survey);



**Survey B:** Right after the individual meeting with the program nurse (second survey);



**Survey C:** 6-12 months following the program nurse's visit (third survey).

The surveys asked questions about what the students know about CE and CLE, if they did the blood test, and if they remember their blood test results.

We met with **359 eligible students** from Secondary 3, 4 and 5.

## Who answered the surveys?

4 out of 10 students did the first survey (A)



2 out of 4 students (53%) did the second (B) survey



2 out of 4 students (54%) did the third (C) survey



1.5 out of 4 students (37%) did all three surveys



0.7 out of 4 students (17%) were either **pregnant** or **had at least one child** when they answered the survey.



0.4 out of 4 students (9%) have **someone in their family** who has/had a child with CE or CLE.



Students who participated were between the ages of 14 and 20 years old. Most were girls.

