# 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).

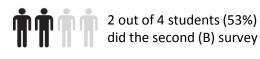
The surveys asked questions about what the students know about CE and CLE, if they did the blood test, and if they remember their blood test results.

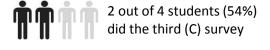
We met with 359 eligible students from Secondary 3. 4 and 5.

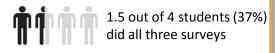
## Who answered the surveys?

4 out of 10 students did the first survey

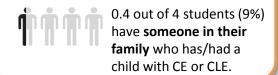












Students who participated were between the ages of 14 and 20 years old. Most were girls.

## What did we find out?

#### KNOWLEDGE

Students know more after the education sessions

Students remember a bit less 6-12 months later than right after the education sessions



But they still remember more 6-12 months after the education sessions than before them

### **BLOOD TEST**

Among those who answered survey C:

86% of students remembered correctly if they did the screening or not.

75% of students did the blood test.

Of those for whom results were available, 88% remembered correctly their blood

test result

# TAKE HOME MESSAGE

- The school education sessions seem to have a **long term positive** effect: students are *learning* about CE and CLE;
- Most students remembered correctly their blood test result 6-12 months after doing the test.

#### Who is doing this evaluation?

The evaluation is a collaborative effort between the Eeyou Awaash Foundation, the Cree Health Board, and a team of researchers from CHU Sainte-Justine, a children's hospital in Montreal. Together, we are doing this evaluation to see how the Cree Health Board's CE-CLE Carrier Screening Program is working.



### CHU Sainte-Justine ResearchTeam

Left: Jessica Le Clerc-Blain (Research Assistant) Middle: Dr Anne-Marie Laberge (Principal Researcher) Right: Dr Andrea Richter (Co-Researcher)

## Valérie Gosselin



Program nurse at the time the surveys were done

#### Who can you call if you have guestions?

- For the CE-CLE carrier screening program, you can contact the Awash Team at your local health clinic;
- For the evaluation that looks at how the program is working, you can call:

Jessica Le Clerc-Blain, Research Assistant **\$ 514-345-4931 #4021** 



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