

WHAT DO HIGH SCHOOL STUDENTS KNOW ABOUT THE CE-CLE CARRIER SCREENING PROGRAM?

What is the CE-CLE Carrier Screening Program?

The CE-CLE carrier screening program was created in 2006 thanks to the efforts of the Eeyou Awaash Foundation and the Cree Health Board to raise awareness in Cree communities about CE and CLE. The program teaches people about CE and CLE, 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. 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 its evaluation to see how it is working.

How does the program work in high schools?

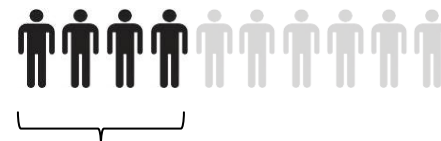
Every year, the program nurse visits all high school students from Secondary 3-5 in every community to give them a presentation on CE and CLE. After, she meets the students individually to ask them if they have questions and if they want to do the blood test. If they do, she takes their blood at school. 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 2 surveys: one right before the educational session with the program nurse (survey A) and one right after their individual meeting with the program nurse (survey B). The surveys ask questions about what the students know about CE and CLE, what they think of the program, if they did the blood test, and why.
- We first visited Waskaganish, after which we made the survey shorter. Because the surveys are now different, we will go back to Waskaganish to re-do the surveys.
- We visited 6 other communities with the new surveys: Chisasibi, Eastmain, Ouje-Bougoumou, Whapmagoostui, Wemindji and Waswanipi (Winter 2014).
- We met with 267 students from Secondary 3, 4 and 5.

Who answered the surveys?

4 out of 10 students did the **first survey**.



2 out of 4 did the **second survey**.

Students who answered the first survey were between the ages of **14 and 20 years old**.
Most were girls.



2 out of 10 participants were either **pregnant** when they answered the survey or **had at least one child**.



1 out of 10 participants have **someone in their family** who had or has a child with CE or CLE.

What have we found so far?

We saw an **increase in knowledge in most questions** about CE and CLE **after** the education session.



8 out of 10 participants said they have **enough or more information** to help them decide about the CE-CLE blood test.



7 out of 10 participants thought it is a **good or very good idea** to offer the CE-CLE blood test in high school.



2.5 out of 10 eligible students **decided to do the blood test** when they met the program nurse individually **after the education session**.

Participants answered that the **most common reasons** for **DOING** the CE-CLE blood test is to **find out for sure if they are a carrier**, and to **avoid giving birth** to a baby with CE or CLE.

Participants answered that the **most common reason** for **NOT doing** the CE-CLE blood test is **not wanting children right now**.

What does this all mean?

The school education sessions seem to have a ***positive effect: students are learning*** about CE and CLE.

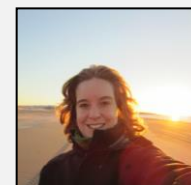
The CE and CLE blood test ***seems to be accepted in high school***.

What is left to do?

- We will visit the high school students in Mistissini, Nemiscau, and Waskaganish in Fall 2014 to ask them to fill surveys A and B (if they want to).
- In the 2014-2015 school year, we will meet with the students who answered the surveys A and B to ask them to answer the last survey (survey C). This survey asks questions on how much students remember about CE and CLE, the blood test, if they shared their results with their family, and what they now think about the program. This will allow us to see how well students understand the presentation, and maybe find ways to improve the education sessions of the program.

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.



Valérie Gosselin
Program nurse



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

Who can you call if you have questions?

- For the CE-CLE carrier screening program, you can call:
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- For the evaluation that looks at how the program is working, you can call:
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