

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?

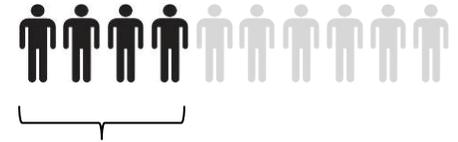
Every year, the program nurse visits all high school students from Secondary 3-5 in every community to give them a presentation on CE and CLE. After, she meets the students individually to ask them if they have questions and if they want to do the blood test. If they do, she takes their blood at school. 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, Uje-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.

