This handout is about the **LIFE-DSR study**.

We are asking you to be in this study because we want to learn more about health in people with Down syndrome.

The study is being done at other locations around the country with other people with Down syndrome too!

A group of people called an IRB reviewed the study. They make sure the study is safe and that study participants like you are protected.
The study takes two years. You will have a few visits to the study site during the time you are in the study. You will come with your study partner. Your study partner will be a family member or caregiver.

During your visits, you will meet with a doctor and a psychologist. You will also get your blood drawn.

The Doctor will ask you questions about your health and will perform a physical exam. You will also get your height, weight, and vital signs, just like when you visit the doctor for check-ups.
You will meet with a psychologist who will ask you some more questions. You may become frustrated, tired, or bored when meeting with the psychologist. You do not have to answer any questions that make you uncomfortable.

You will come back two more times to see the doctor and the psychologist and get your blood drawn. This will happen 1 year after your first visit and one more year after your second visit.

If you have any questions, you can ask a member of the study team.

The study is private. No one will share your name and address or know that you are participating in the study.
Information may be shared with your study partner.

You do not have to be in the study if you do not want to. You can say no to being in the study at any time, even if your study partner has said that you should participate.

No one will be mad at you if you say no. Your doctor will still take care of you. You just need to tell the study doctor and your study partner that you want to stop.

Thank you for watching our video about the LIFE-DSR Study. If you have any questions about this video, you can ask your study partner or the study coordinator.

Photo Credits
Map: https://www.lumindrds.org/ds-ctn/