

Frequently Asked Questions: All Samples

What is the AFM Biorepository about?

The Acute Flaccid Myelitis Biorepository (Biorepository) was developed and funded by the Centers for Disease Control and Prevention (CDC) to



samples from individuals suspected to have acute flaccid myelitis (AFM).

What is a biorepository?

A biorepository is a facility that collects and stores samples of biological material. This material could include blood, urine, tissue, cells, DNA, and proteins. Some medical information may also be stored along with a written consent form. These samples will be used for future research.

Who is managing the Biorepository?

CDC funds the Biorepository. CDC is a federal public health agency located in Atlanta, Georgia. McKing Consulting Corporation (McKing) has a contract to collect, distribute, and manage the integrity of samples for the Biorepository.

Why is this Biorepository important?

The samples in the Biorepository will help researchers identify a cause and/or risk factors for AFM. Because the number of cases of AFM varies over time, the Biorepository will help make sure samples are available when scientists need them, like when they have a new idea for the cause of AFM.

Who can take part in the Biorepository?

Anyone who is suspected to have AFM can take part if they are not being treated at a hospital enrolled in the NIH study.



What information about me/my child will be collected?

You will be asked to sign a consent form and answer a few brief questions. You will be asked to provide blood, stool, and a nasal swab or nasal wash at the hospital. We would also like to store any samples that were left over from those taken for diagnosis. If you agree, a medical professional (phlebotomist) will draw two tubes of blood at a later date. The samples will be stored for future research on AFM.



Where will the samples be collected?

The first samples will be taken at the hospital. Blood will be taken at a later date. We will contact you to set up a time for a trained professional to come to your home or similar location and draw your blood.

Is there any risk to me?

There is very little risk. We will try to make you as comfortable as possible but taking your blood may hurt a little. You will feel a slight pinch when the needle is put in. You may feel some discomfort or see a small bruise where the blood was drawn. The nose swabs or swabs collected from the back of the throat may be uncomfortable, but they do not carry any risk. It is normal to see a small amount of blood after the swab is taken.

Is there any benefit to me?

There is no direct benefit to you. The Biorepository will collect, store, and process samples, but your samples may help us to better understand AFM in the future.

Will the information I tell you be kept private?

Yes. Just like when you talk to your doctor, everything you tell us will be kept private to the extent allowed by law. Any information with your name on it will be kept in a locked area. Only authorized employees will be able to look at this information. Individuals will not be identified.

What will happen after I provide samples?

Results of research using samples from the Biorepository will be summarized and posted on the CDC website for any interested persons to view. Individuals will not be identified. CDC will keep your samples for future AFM research.

Is there anything I need to do to prepare prior to the day I have the samples collected?

No.

Is there anything I need to do on the day I have the samples collected?

Yes. Drink plenty of water on the day of your blood draw.

How long will it take?

Each sample collection should take about 30 minutes.

Is there any cost to me for the blood sample collection?

No. There is no charge for sample collection.

March Instal

Do I have to take part in the Biorepository?

No. Taking part in the Biorepository is completely voluntary. You can refuse to take part at any time. Your decision will have no impact on your medical care.

What if I am not/my child is not diagnosed with AFM?

The Biorepository will collect and store samples of suspected AFM cases. If you or your child is not diagnosed with AFM after testing, we will still store your samples with your consent. All samples, even those from individuals not diagnosed with AFM, are still valuable to be able to compare with other samples.

For more information about the Biorepository, contact Laurie Wagner, Biorepository Coordinator Toll-free: 855-874-6912 Email: AFMproject@secure.mcking.com Website: CDC's AFM Page