

SCRIPPS CLINIC BIO-REPOSITORY

Information Sheet

❖ **What is the Scripps Clinic Bio-Repository?**

Scripps Clinic & Scripps Health is developing a resource for physicians and scientists to have access to blood and tissue samples, along with patient health information, located in one place (a Bio-Repository) to conduct research on many diseases and health conditions.

❖ **What is a Bio-Repository?**

A Bio-Repository is a collection of human biological materials (e.g. tissue samples, urine, saliva and blood etc). Although the term might be applied to any collection of biological samples, “Bio-Repository” is often used as short-hand for tissue samples linked to genetic information and/or a person’s medical history. Bio-Repositories are sometimes called “BioBanks”, “DNA banks” or “genetic databases”.

❖ **Why are Bio-Repositories important?**

Increasingly, researchers use bio-repositories to study genetic factors in health and disease. Using the stored genetic material and information, researchers do work that may lead to the development of new diagnostic tests and targeted or personalized treatments for diseases. One of the goals of the Scripps Clinic Bio-Repository is to help translate scientific discoveries made in the laboratory into new treatments and improved health for Scripps patients and throughout the world.

❖ **Who is eligible to participate?**

The Scripps Clinic Bio-Repository is currently looking for enrollees who receive care within the Scripps Health system.

❖ **What do I need to do?**

Participation in the Scripps Clinic Bio-Repository is voluntary. If you decide to participate, you will review a document that will describe the study in more details. If you have any questions, please do not sign the document. Instead, indicate that you have a question and your physician or physician’s assistant will further discuss this with you. If you agree to participate, you will be asked to complete a very brief questionnaire/consent form. Any samples you consent to will be collected for this study during your clinic visit today and on any re-occurring clinic visits.

❖ **How long will my samples be stored?**

Your samples will be stored for an indefinite period of time unless you ask for your samples to be removed.

❖ **Confidentiality?**

The data that we obtain from you will be strictly confidential. You will be assigned a study number which is a unique identifier in our database and on your samples. This makes you completely anonymous to everyone except the research team. This database is stored on a secure server in a department that routinely handles sensitive information and procedures are in place to ensure the highest possible data security and integrity. Any data released to researchers will be in an electronic form and will be fully anonymous; it will contain no means of identifying you. If your samples are released for further analysis to clinical/scientific collaborators (e.g. academia or industry), those researchers can request information such as your BMI, age, blood sample results etc., which will enable them to analyze their data. However, none of your personal information or data that could be traced to you will be released.