

A few weeks ago I had the pleasure of attending the Turner Syndrome Foundation holiday party. I had the privilege of meeting a lot of wonderful families and I enjoyed hearing your stories.

For those whom I did not get a chance to talk with, I am the genetic counselor for the NIGMS Repository at the Coriell Institute for Medical Research. The NIGMS Human Genetic Cell Repository is a biobank that stores well characterized, high quality cell lines for use in research. To make a cell line, human cells are taken from a blood or tissue sample and placed in a container with a growth solution. This process is called *cell culturing*. The cultured cells can then be “harvested”, frozen, and stored indefinitely. Information about the medical and family history of the sample donor is also collected. To protect the privacy of sample donors, samples are coded with a number and all names, dates of birth or other potentially identifying information is removed. Scientists can later access banked cells and corresponding clinical information and use them for a variety of purposes, including: finding new genes, studying how cells function, and developing new ways to diagnose and treat genetic diseases like Turner syndrome.

When individuals who have Turner syndrome donate a sample to a cell repository, they are providing scientists with the very valuable opportunity to learn more about their specific disease. One of the key barriers to finding treatments or cures for rare, genetic diseases is the lack of available human cell and tissue resources for scientists to use to test potential drug compounds or gene or cell based therapies. Testing candidate drugs or therapies using cells from individuals with rare genetic diseases can help scientists determine which approaches are most likely to work and be safe enough to test further in human clinical trials.

Currently, the NIGMS Repository has 22 samples from individuals with Turner syndrome. Many of these samples have very limited information on the specific features of Turner syndrome that were present in the sample donor. Our goal is to continue to build our collection of Turner syndrome samples to create a larger, more diverse and more valuable resource for scientists studying the causes of and potential treatments for individuals with Turner syndrome. Part of what makes samples more valuable is the availability of detailed clinical information. This is why we ask sample donors to provide copies of relevant medical records.

Banking for the future by donating a sample to a cell repository is an investment that has the potential to greatly accelerate, improve and advance scientific research on Turner syndrome. Please consider donating a sample to the NIGMS Repository at Coriell. To learn more, please contact me at 856-757-4822 or [tschmidl@coriell.org](mailto:tschmidl@coriell.org). You can also read more about the sample donation process on our [webpage](#).

Thank you again to those who have already donated samples!

Sincerely,



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