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Epilepsy work is a 'national treasure'

San Francisco Business Times - by [Ron Leuty](#)

To understand more about epilepsy, Dr. Dan Lowenstein and colleagues are going straight to the source: patients.

It's a daunting task for the Epilepsy Phenome/Genome Project, based at the **University of California, San Francisco**. Working with 22 other epilepsy centers in the United States and one each in Australia, Canada and Argentina, researchers are gathering blood samples from 1,500 pairs of patients — siblings or parent-child pairs, for example — with unexplained epilepsy plus 750 individuals with rare forms of epilepsy that the parents did not have.

In the third year of a five-year, \$15 million grant from the **National Institute of Neurological Disorders and Stroke**, researchers are close to gathering the 2,000th patient. "We're at 62 percent of where we wanted to be at this time," said Lowenstein, a professor of neurology at UCSF and director of the epilepsy project.

The blood samples are banked for future research, available after a two-year embargo to investigators forever. Answers to survey questions — aimed at discovering more about what epileptic seizures are like, when they occur and how often they happen — and brain scans are loaded onto a central database.

"We're a network," said Lowenstein, who conceived the project eight years ago with Dr. Ruben Kuzniecky of **New York University**. "It really is a research enterprise without walls."

Housing the administrative and informatics aspects of the project at UCSF, though, has translated into about a dozen jobs.

It is just the beginning, Lowenstein said. A robust database holding the genomic makeup of epilepsy patients as well as anecdotal information could combine with the shrinking cost of genome sequencing — now as low as \$1,000 from millions of dollars just a few years ago — to accelerate research of a largely treatable but incurable disease.

In the United States, epileptic seizures affect 2.75 million people.

"We have described (the database) as a national treasure of genetic material for experiments we haven't thought of yet," Lowenstein said.



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"It really is a research enterprise without walls," says researcher Dan Lowenstein.

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