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Huntington·Study·Group

The following information is a script of information that was aired on (U.S.) National Public Radio NewsCasts, on December 8, 2008 (evening report) and again on December 9, 2008 (morning report), by Richard Knox. The report is in reference to the Huntington Study Group article "Communicating Clinical Trial Results to Research Participants", which was published in the Archives of Neurology on December 8, 2008.

<INTRO> People who participate in medical studies often don't find out about the results. Some researchers are trying to do something about that. NPR's Richard Knox reports.

<KNOX> More than two million Americans take part in studies every year. But there's no requirement that the drug companies, study authors or government funding agencies inform volunteers about the outcome. The only exception is when a study turns up evidence of harm.

Researchers at the University of Rochester decided to do things differently in a study of an experimental drug for Huntington's disease, a nerve disorder. The company that funded the study agreed to develop a plan to inform the 316 participants of the outcome. Study coordinators called each one. They were invited to participate in a conference call to summarize the findings and answer questions.

As it turned out, the drug didn't work. But the authors hope they've set a new standard of openness for medical studies.

Richard Knox, NPR News