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Rare Sharing of Data Leads to Progress on Alzheimer's

By **GINA KOLATA**

In 2003, a group of scientists and executives from the [National Institutes of Health](#), the [Food and Drug Administration](#), the drug and medical-imaging industries, universities and nonprofit groups joined in a project that experts say had no precedent: a collaborative effort to find the biological markers that show the progression of [Alzheimer's disease](#) in the human brain.

Now, the effort is bearing fruit with a wealth of recent scientific papers on the early diagnosis of Alzheimer's using methods like PET scans and tests of spinal fluid. More than 100 studies are under way to test drugs that might slow or stop the disease.

And the collaboration is already serving as a model for similar efforts against [Parkinson's disease](#). A \$40 million project to look for biomarkers for Parkinson's, sponsored by the [Michael J. Fox Foundation](#), plans to enroll 600 study subjects in the United States and Europe.

The work on Alzheimer's "is the precedent," said Holly Barkhymer, a spokeswoman for the foundation. "We're really excited."

The key to the Alzheimer's project was an agreement as ambitious as its goal: not just to raise money, not just to do research on a vast scale, but also to share all the data, making every single finding public immediately, available to anyone with a computer anywhere in the world.

No one would own the data. No one could submit patent applications, though private companies would ultimately profit from any drugs or imaging tests developed as a result of the effort.

“It was unbelievable,” said Dr. John Q. Trojanowski, an Alzheimer’s researcher at the [University of Pennsylvania](#). “It’s not science the way most of us have practiced it in our careers. But we all realized that we would never get biomarkers unless all of us parked our egos and intellectual-property noses outside the door and agreed that all of our data would be public immediately.”

Biomarkers are not necessarily definitive. It remains to be seen how many people who have them actually get the disease. But that is part of the research project.

The idea for the collaboration, known as [ADNI](#), for Alzheimer’s Disease Neuroimaging Initiative, emerged about 10 years ago during a casual conversation in a car.

Neil S. Buckholtz, chief of the Dementias of Aging Branch at the [National Institute on Aging](#), was in Indianapolis, and Dr. William Potter, a neuroscientist at Eli Lilly and his longtime friend, was driving him to the airport.

Dr. Potter had recently left the National Institutes of Health and he had been thinking about how to speed the glacial progress of Alzheimer’s drug research.

“We wanted to get out of what I called 19th-century drug development — give a drug and hope it does something,” Dr. Potter recalled in an interview on Thursday. “What was needed was to find some way of seeing what was happening in the brain as Alzheimer’s progressed and asking if experimental drugs could alter that progression.”

Scientists were looking for biomarkers, but they were not getting very far.

“The problem in the field was that you had many different scientists in many different universities doing their own research with their own patients and with their own methods,” said Dr. Michael W. Weiner of the San Francisco [Department of Veterans Affairs](#), who directs ADNI. “Different people using different methods on different subjects in different places were getting different results, which is not surprising. What was needed was to get everyone together and to get a common data set.”

But that would require a huge effort. No company could do it alone, and neither could individual researchers. The project would require 800 subjects, some with normal memories, some with memory impairment, some with Alzheimer’s, who would be tested for possible

biomarkers and followed for years to see whether these markers signaled the disease's progression.

Suddenly, in the car as he drove Dr. Buckholtz to the airport, "everything just jelled," Dr. Potter said, adding, "Maybe this was important enough to get people to work together and coordinate in a way that hadn't been possible before."

The idea, Dr. Buckholtz said, was that the government's National Institutes of Health "could serve as an honest broker between the pharmaceutical industry and academia."

Soon, Dr. Richard J. Hodes, the director of the National Institute on Aging, was on the phone with Dr. Steven M. Paul, a former scientific director at the National Institute of Mental Health who had recently left to head central-nervous-system research at Eli Lilly. Dr. Paul offered to ask other drug companies to raise money.

It turned out to be relatively easy to get companies to agree, Dr. Paul said. It had become clear that the problem of finding good diagnostic tools was huge and complex. "We were better off working together than individually," he said.

A critical aspect of the project was the [Foundation for the National Institutes of Health](#), which was set up by Congress to raise private funds on behalf of the institutes. Dr. Paul was on its board.

In the end, the National Institute on Aging agreed to pay \$41 million, other institutes contributed \$2.4 million, and 20 companies and two nonprofit groups contributed an additional \$27 million to get the project going and sustain it for the first six years. Late last year, the institute contributed an additional \$24 million and the foundation was working on a renewal of the project for another five years that would involve federal and private contributions of the same magnitude as the initial ones.

At first, the collaboration struck many scientists as worrisome — they would be giving up ownership of data, and anyone could use it, publish papers, maybe even misinterpret it and publish information that was wrong.

But Alzheimer's researchers and drug companies realized they had little choice.

“Companies were caught in a prisoner’s dilemma,” said Dr. Jason Karlawish, an Alzheimer’s researcher at the University of Pennsylvania. “They all wanted to move the field forward, but no one wanted to take the risks of doing it.”

Many people look askance at collaborations with drug companies, and often that attitude is justified, Dr. Karlawish said.

But not in this case. To those who are skeptical, he says, “My answer to them is ‘get over it.’ ”

He went on: “This one makes sense. The development of reliable and valid measures of Alzheimer’s disease requires such large science with such limited returns on the investment that it was in no one company’s interest to pursue it.”

Companies as well as academic researchers are using the data. There have been more than 3,200 downloads of the entire massive data set and almost a million downloads of the data sets containing images from brain scans.

And Dr. Buckholtz says he is pleasantly surprised by the way things are turning out.

“We weren’t sure, frankly, how it would work out having data available to everyone,” he said. “But we felt that the good that could come out of it was overwhelming. And that’s what’s happened.”