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Patients Share DNA for Cures

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Patients with rare and deadly diseases are getting a powerful new boost.

Cancer foundations and other nonprofit patient groups are investing tens of millions of dollars to build genetic databases in an effort to speed drug development and jumpstart clinical trials.

The databases are designed to collect DNA and other information from patients with hard-to-treat diseases. The material can be analyzed for certain genetic mutations and made available to scholars and pharmaceutical companies.

The databases could also help patients familiar with their own genetic mutations to find information about clinical trials.

On Tuesday, the Leukemia & Lymphoma Society is set to announce a three-year, \$8.2 million project that combines the resources of the Oregon Health Sciences University, gene-sequencing company Illumina Inc., and [Intel Corp.](#) [INTC +0.29%](#) Funded by the society, the resulting database will contain DNA information and analysis gathered from 900 patients with acute myeloid leukemia.

[Array Biopharma Inc.](#) [ARRY -0.39%](#) is the first of what the society expects will be a host of companies that will test new and existing compounds against any potential drug targets revealed in the patient data.

The plan is to have clinical trials for relapsed AML patients underway within one year and for newly-diagnosed patients by the end of the second year. "We're talking about an aggressive timeline for moving this data into the clinic," says Brian Druker, director of the Knight Cancer Institute at OHSU and leader of the project.

Next week, the Multiple Myeloma Research Foundation is hosting a symposium in New York City where it plans to reveal the first data from an ongoing \$40 million, 1,000-patient study. Called Compass, the project is dedicated to mapping the genetic and clinical characteristics of the blood cancer.

The organization is making raw data from the study available to academic and industry researchers that could help them find information about at least 10 different mutations believed to fuel the cancer.

"Our goal is to accelerate cures," says Kathy Giusti, founder and chief executive officer of the foundation.

One factor that makes the DNA databases possible is the rapidly declining cost of DNA sequencing. "The cost to sequence 900 patients a decade ago—that would have been an impossible project to fund," Dr. Druker says. "Now it's actually a reasonable amount of money."

George Mulligan, director of translation medicine at [Takeda Pharmaceuticals Inc.'s 4502.TO +1.18%](#) Millennium Pharmaceuticals unit, says groups like the myeloma foundation can serve as an "honest broker" with "the influence and the clout" to bring a variety of research interests together. Millennium developed Velcade, a multiple-myeloma drug.

The myeloma foundation has raised nearly \$250 million since it was founded in 1998, when the median survival rate was about 3-1/2 years. Thus far, the organization has supported 47 trials involving 24 drugs, six of which have reached the market.

To make their money work even harder, patient foundations increasingly make grants contingent upon researchers agreeing to share data and expertise—even with potential competitors. They say that such open access allows the research enterprise as a whole to operate more efficiently than just one drug company or academic group working alone. "We see ourselves as a catalyst for collaboration," says John Walter, chief executive of the leukemia group. "It's not a conventional approach."

While cancer groups are paving the database route, others— focusing on disparate conditions including Parkinson's disease—are following a similar path. Later this year, the Michael J. Fox Foundation will begin enrolling the first of 600 patients in a Parkinson's disease study, hoping to gain insight into how two recently discovered genetic mutations affect progression of the debilitating condition. The DNA data will complement an ongoing \$50 million study co-funded by 13 drug companies to identify other biological markers of Parkinson's so researchers can better study potential treatments.

All three foundations have made their mark promoting this kind of collaborative research—efforts that have helped several drugs come to market.

The Michael J. Fox Foundation, founded in 2000 by the actor after his Parkinson's diagnosis two decades ago, has funded the development of several research tools, including chemicals and animal models of the disease. Last week, Biogen Idec Inc. and Amicus Therapeutics Inc. announced an agreement to pursue possible Parkinson's drugs based on research at Amicus that the foundation supported.

A big hurdle for Parkinson's drugs is a lack of validated biological markers that enable researchers to track whether a treatment is actually working. "It's made it very high-risk [for companies] to move forward with these types of therapies," says Todd Sherer, CEO of the foundation. The \$50 million collaboration between the foundation and 13 drug companies is an effort to address that issue while reducing the risk to individual firms.

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