A new era of venture philanthropy

In hopes of boosting the development of new drugs to treat a deadly condition, the Cystic Fibrosis Foundation entered into what has been termed "venture philanthropy." That approach creates a set of relationships with potential conflicts of interest, each marked with a red flag.

B

The foundation provides $75 million to Vertex Pharmaceuticals for the development of Kalydeco, the first drug to treat the root causes of cystic fibrosis. The foundation gets a percent of Kalydeco sales, but does not seek pricing controls on the expensive drug.

C

In 2012, Kalydeco comes on the market. It is only effective for about 4% of those with cystic fibrosis, or 1,200 Americans. Kalydeco sales this year are projected to hit $300 million worldwide. Analysts say the drug eventually will bring in billions annually if it can be combined with other drugs to treat larger numbers of cystic fibrosis patients.

D

The foundation issues treatment guidelines for cystic fibrosis in April 2013. Of the 10 members on the guidelines panel, four were from institutions that received foundation grants and three worked for the foundation. The foundation employees did not take part in Kalydeco talks.

E

Doctors

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F

Kalydeco costs about $307,000 a year. Nearly all of the cost is picked up by public or private insurance.

G

A share of Kalydeco sales goes to the foundation. Last year, the foundation sold a portion of its rights to Kalydeco royalties to an undisclosed firm for $150 million. It is using that money to fund more drug development work with Vertex and other drug companies. It will get a percent of sales of any new drugs.

Source: Journal Sentinel