Wall Street Journal: ***How Lobbying for Rare Disease Research Influences Congress and NIH***
November 13, 2014

For years, patient advocates and families have lobbied Congress for more funds to combat rare diseases. But to what extent does lobbying make a difference when Congress sets appropriations and the National Institutes of Health makes funding decisions?

A new study suggests lobbying by private groups does, indeed, influence federal funding for rare disease research. Every dollar spent on lobbying generated congressional support in the form of soft earmarks, which are passages in an appropriations bill that urge or encourage spending but do not carry the rule of law. In this instance, the term refers to providing funding for NIH research into particular diseases.

As lobbying increased between 1998 and 2008 – the stretch of time examined in the study – so did the number of soft earmarks attributed to the lobbying, although the trend varied some years. Similarly, the study found the pattern then extended to NIH allocations for research grant solicitations, known at the agency as requests for applications and program announcements.

Just the same, lobbying efforts on behalf of rare disease research may only affect a relatively small portion of such federal funding. The share of overall NIH funding for new projects on rare diseases that could be attributed to soft earmarks between 1998 and 2008 ranged anywhere from only 3% to 15%, according to the study, which is being published in Management Science.

Some critics have complained that such lobbying sways decision makers to unfairly divert funds from other areas of promising research. But study co-author Deepak Hegde, who is an assistant professor of management and organizations at the New York University Stern School of Business, maintains lobbying can alert Congress to the toll that rare diseases take on society, as well as new medical literature.

In that way, he suggests that such lobbying may not actually distort public science. "Lobbying may be transmitting information about the public burden [of rare diseases] and scientific opportunities [for research] into the allocation process that might not otherwise use this information," says Hegde. "It may have a beneficial effect, but we don't have a conclusive way of establishing that."

Of course, patient advocates – and most people, for that matter – are likely to maintain that lobbying is worthwhile. Just the same, the findings may hearten patient groups, which have become increasingly active in recent years as they push Congress, lawmakers, the pharmaceutical industry and regulators to do more to find salves for rare diseases.

"Remember that NIH has to pay attention to what the appropriators in Congress want, because they're dependent on getting funding," says Hegde. "So our conclusion about soft earmarks is a more nuanced finding, but does indicate that soft earmarks are effective. And for the most part, I don't think people are aware of the mechanisms through which allocations are made.