

Necessary Relationships: The Effect of Pharmaceutical Relationships on Rare Disease Patient Advocacy Organizations

"The ultimate goal for most rare disease patient advocacy organizations is to bring more treatment options to market. Relationships between these organizations and the pharmaceutical industry lead nonprofit organizations toward mission fulfillment through funding research and serving patients, and have a positive effect on mission impact. As nonprofit organizations are duty-bound to remain independent and uphold their missions, these relationships should not be considered unethical.

Rare disease patient advocacy organizations view relationships with industry as positive and ethical. Organizations actively involved in pharmaceutical relationships overwhelmingly report positive effects on their organizations.

The rare disease patient advocacy community welcomes pharmaceutical partnerships. Organizations are encouraged to continue partnering with industry as the patient voice evolves, helping patients through integrative collaboration.

In rare disease, patients' lives are on the line while they wait for treatment options. Thus, it can be argued from the standpoint of patient advocacy and the nonprofit sector that potentially slowing drug development in the name of ensuring ethical pharmaceutical relationships is unethical itself."

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