I am often asked, “Why a nonprofit?”

Nonprofit organizations improve our quality of life. By offering services that are underwritten by both the private sector and government. Our communities are supported by a lower-tiered level of demand compared to businesses, government, and nonprofits.

The private sector, or businesses, addresses consumer needs that are consumed by economic forces. Government, on the other hand, addresses needs that are publicly visible but not necessarily for the larger good. Nonprofit organizations focus, first and foremost, on the individual and the group. They address needs that are in the best interest of the common good. It is organizations like Odylia that recognize the need to move beyond the traditional commercial model of treating rare diseases.

I often find that people respond to the definition of nonprofit as the organization that cannot make money. In fact, nonprofits can and should be in every ecosystem where there is a need, be it an academic, a medical, a governmental, or a commercial one. While not all nonprofits will run a profit, they will have some form of revenue structure to sustain their programs and meet their mission.

We are excited by all that has been accomplished in five years and look forward to even more in the coming years. Help us celebrate by making a gift of $55.55 to support our mission to accelerate drug development for rare diseases. March 2023

Support Odylia! Together we can make a difference!

“I said “Somebody should do something about that.” Then I realized I am somebody.”

— Lily Tomlin

I knew there was a better way to develop treatments for rare diseases. When the idea for Odylia was born, we realized that there was a need for an organization that could take on the challenge of developing treatments for rare disease patients through a drug development process unhindered by commercial constraints on decision-making.

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Many of the pivotal breakthroughs in gene therapy for genetic diseases are due to the pioneering work of Odylia. The company has made significant contributions to the field, including the development of the first successful gene therapy for the treatment of a genetic disorder.

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The RPGRIP1 gene therapy program (OT-004) continues to show promise in the treatment of RPGRIP1-related retinopathy. Our criteria for moving a program forward centers on three questions: Do we have the technology or scientific know-how to make a therapeutic? Is it safe? Is it effective? These three criteria drive decision-making. We work on programs that do not usually fit into industry’s model, to ensure the entire community is served. Our work complements, expands, and rebalances the efforts of our partners in the private and public sectors.

It may be the second approach, but it is exciting.

For a fascinating review of philanthropy that dates back to the 1500's, visit the National Philanthropic Trust's Global Genes Conference.

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