ALPHA-1 FOUNDATION
ABSTRACT SUBMISSION: "INDIVIDUALS SEEKING CURES"
WORLD HEALTH CARE INNOVATION AND TECHNOLOGY CONGRESS

How can you "cure" a genetic disease that is the leading cause of genetic emphysema and liver disease? A group of patients with Alpha-1 Antitrypsin Deficiency (Alpha-1) have developed an innovative strategy to do just that. They established the **Alpha-1 Foundation**, an organization with a straightforward mission: to provide the leadership and resources that will result in increased research, improved health, worldwide detection and a cure for Alpha-1. The founders also established an independent not-for-profit organization, **AlphaNet**, to provide comprehensive care to individuals with Alpha-1 and generate a revenue stream to support the research mission of the Foundation. AlphaNet coordinates services for more than 2,700 individuals with Alpha-1 generating over $2.7 million in contributions annually to the Foundation, totaling over $14 million since 1995.

The Foundation's initial focus was to eliminate the impediments to research by creating the infrastructure to accelerate research and avoid unnecessary duplication of scientific resources. The Foundation's Alpha-1 Research Registry, the Alpha-1 DNA & Tissue Bank, the Alpha-1 International Genetics Reference Laboratory, and its Clinical Resource Centers provide the capability to support clinical research, and facilitate clinical trials. This infrastructure attracted over 12 new biopharmaceutical companies to initiate therapeutic development resulting in 2 recently licensed drugs; several next generation development programs; an ongoing gene therapy trial (phase 1); and identification of several novel approaches in early development.

In the last ten years, the Foundation has funded more than $19 million in research grants and programs and has become a model for other organizations finding cures for rare diseases.

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