



*****FOR IMMEDIATE RELEASE*****

Miami, January 31, 2020 – The Alpha-1 Foundation is proud to celebrate its 25th Anniversary. On January 31, 1995, the Alpha-1 Foundation was incorporated as a not-for-profit organization by its three co-founders, John W. Walsh, Sandy Lindsey and Susan Stanley.

The Foundation was created because the National Heart, Lung, and Blood Institute of National Institutes of Health (NIH) was winding down its huge seven-year study of Alpha-1 Antitrypsin Deficiency and John W. Walsh recognized that no further resources were going to be put towards Alpha-1 research. Three determined “Alphas” co-founded the organization.

Alpha-1 Antitrypsin Deficiency (Alpha-1) is a rare genetic (inherited) condition – it is passed from parents to their children through their genes. Alpha-1 may result in serious lung disease in adults and/or liver disease at any age.

Walsh’s leadership and passion helped shape the Foundation into a successful organization by establishing a broad range of activities and programs including the Alpha-1 Research Registry, the Alpha-1 DNA & Tissue Bank, the Alpha-1 Research Network, International Scientific Conferences, and the Gordon L. Snider Critical Issues Workshop series. A majority of the Board of Directors is either diagnosed with Alpha-1 or has a family member diagnosed with Alpha-1.

“Thank you to all of you who have contributed to the Alpha-1 Foundation with your time and resources. The Foundation is proud of the advances made over the last 25 years and the services that we have given to our community. Achieving the mission remains our focus. We want to deliver on the promise of a cure and the vision of our founders,” said Miriam O’Day, president & CEO of the Foundation.

Founded in 1995 by the same individuals who started the Foundation, AlphaNet was established to provide health maintenance and support services to the Alpha-1 community, with the clear mission of coordinating and consolidating low-cost health services designed exclusively for individuals with Alpha-1, while generating a consistent source of revenue to support the research mission of the Foundation. AlphaNet is the largest contributor of the Foundation, with contributions exceeding \$60 million to date.

“As we celebrate 25 years of service to the Alpha-1 Community, we honor the singular John Walsh and the visionary Bob Barrett whose synergy fostered the success of AlphaNet’s uniquely impactful model, ‘Alphas Serving Alphas’. Every single achievement at AlphaNet starts with a phone call from an Alpha coordinator to an Alpha subscriber. We are fortunate to have (and have had) so many selfless Alphas work as coordinators in service of other Alphas. AlphaNet’s

accomplishments also depend on the support of our pharmaceutical partners, namely Grifols, CSL Behring, and Takeda, who represent the very best in corporate commitment to their patients. We also acknowledge the work of specialty pharmacies like Accredo, Coram CVS, Diplomat, and Eversana who send caring nurses out to Alpha homes each week. Finally, we recognize AlphaNet's devoted volunteer Board of Directors who upheld a level of empathy and effectiveness needed for such long-term success. We are fortunate to be part of something so special," said Mark Delvaux, president & CEO of AlphaNet.

With the help of the Alpha-1 community, the Foundation has designed and launched new programs and developed a solid infrastructure to promote research and the development of new therapies for improving the quality of life for those diagnosed with Alpha-1. It has fostered collaborations with investigators throughout the United States and Europe, working closely with the National Institutes of Health (NIH), the U.S. Food and Drug Administration (FDA), the pharmaceutical industry, and Alphas to expedite the development of improved therapies.

"As we commemorate the 25th anniversary of the Foundation, I consider it a great privilege to chair the Foundation's Board of Directors as we remain steadfast in our efforts toward a cure for Alpha-1. The achievements of the Foundation in this first 25 years are impressive and can be attributed to their ability to bring all constituents to the table with a patient-focused approach to accelerate innovative approaches to this disease," said Jeanine D'Armiento, chair of the Board of Directors at the Foundation.

The Alpha-1 Foundation is committed to finding a cure for Alpha-1 Antitrypsin Deficiency (Alpha-1) and to improving the lives of people affected by the condition worldwide.

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About the Alpha-1 Foundation

The Alpha-1 Foundation, founded in 1995, is committed to finding a cure for Alpha-1 Antitrypsin Deficiency (Alpha-1) and to improving the lives of people affected by the condition worldwide. The Foundation has invested over \$76 million to support Alpha-1 research and programs at 116 institutions in North America, Europe, the Middle East, and Australia.

For more information, visit www.alpha1.org.

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