



## **About the Alpha-1 Foundation**

The Alpha-1 Foundation is a not-for-profit organization that raises awareness of Alpha-1 Antitrypsin Deficiency (Alpha-1) and funds research to find a cure for the condition, along with related programs. It is the leading national organization serving the Alpha-1 community and has been successful in building the necessary infrastructure to encourage Alpha-1 research worldwide.

Alpha-1 is a genetic condition which is passed from parents to children through genes. It may cause lung disease in adults and/or liver disease at any age. Anyone with chronic breathing problems or unexplained liver disease should take a simple blood test to rule out Alpha-1.

The Foundation has invested more than \$86 million to support Alpha-1 research and programs at 120 different institutions in North America, Europe, the Middle East and Australia, and has programs to ensure that people who are affected by Alpha-1 have the support, education and advocacy they need to improve their quality of life and maintain access to lifesaving therapies.

Areas of focus include:

- Research:
  - World's largest Alpha-1 Research Registry
  - Alpha-1 Foundation DNA and Tissue Bank
  - Alpha-1 Research Lab at the University of Florida
  - The Alpha-1 Clinical Resource Center Network, which



has 76 centers throughout North America and one in Canada, that specialize in patient care and education

- Hosting scientific conferences, workshops and working groups that bring scientists together to focus on Alpha-1
- Encouraging Alphas to participate in research programs
- Helping Alphas develop an enhanced, healthier sense of personal identity and a connection with the larger Alpha-1 community through a network of more than 80 Support Groups nationwide, as well as a Patient Information Line and a Genetic Counseling Program
- Hosting national and regional education programs that reach more than 5,000 Alphas, their families, and healthcare professionals
- Facilitating a grassroots network to advocate for Alphas
- Producing a magazine – *Alpha-1-To-One* – as well as monthly newsletters and many educational brochures and publications to keep the community up to date

*For more information, visit [www.alpha1.org](http://www.alpha1.org) or call 1-877-228-7321.*