

## Biobanks

The Alpha-1 Foundation maintains a central repository of DNA, plasma, tissue samples and phenotypic data of individuals with Alpha-1, Alpha-1 carriers and normal controls at the University of Florida (Mark Brantly, MD, Director).

Other sources of Alpha-1 lung tissue, plasma, DNA and phenotypic data include the LTRC, NHLBI, and the Foundation's own Alpha-1 Biomaterials Exchange. The Alpha-1 Biomaterial Exchange is an open resource for both academia and industry that works by matching one investigator (in need of biomaterial) with another investigator (supplier of biomaterial). Both can be accessed through the Alpha-1 Foundation.

## More Research Information

The Investigators tab on the Alpha-1 Foundation website ([www.alpha1.org](http://www.alpha1.org)) offers more information for Alpha-1 researchers. Additional resources are on our website which include links to other Alpha-1 related websites, a listing of current Foundation-sponsored scientific meetings and conferences, the Foundation's Research Portfolio, and more.

## Contact Information

Researchers who need biomaterial samples or additional information about the Alpha-1 Foundation's research programs and grant opportunities should contact Vanessa Valencia, Manager of Grants Administration, at [vvalencia@alpha1.org](mailto:vvalencia@alpha1.org) or 877-228-7321, ext. 242.

*Cover photo courtesy of Boston University.  
Photographed by Jackie Ricciardi.*



The Alpha-1 Foundation is committed to finding a cure for Alpha-1 Antitrypsin Deficiency and to improving the lives of people affected by Alpha-1 worldwide. Leading experts in the field of Alpha-1 research are working with the Foundation through their participation on the Board of Directors, as members of the Medical and Scientific Advisory Committee, directing Clinical Resource Centers, as members of Working Groups, or as participants at Foundation-sponsored scientific conferences and workshops. These experts, together with respected members of the Alpha-1 medical, professional, scientific, and patient communities are teaming up with the Alpha-1 Foundation to identify the most critical areas of research and support the development of new therapies. Importantly, the Alpha-1 Foundation has also formed collaborative relationships with government and industry to promote needed research and create awareness of this genetic disorder.

[www.alpha1.org](http://www.alpha1.org)

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# The Alpha-1 Foundation Research and Resource Opportunities



Research to find better  
treatments and ultimately  
a cure for Alpha-1





Alpha-1 Antitrypsin Deficiency (Alpha-1) is a genetic condition that leads to decreased circulating levels of alpha-1 antitrypsin (AAT) and significantly increases the risk of serious lung disease in adults and liver disease in infants, children and adults. There currently is no cure available for this condition.

Promoting research to find better treatments and ultimately a cure for Alpha-1 is a core mission of the Alpha-1 Foundation. Investigator-initiated grants have been the driving force of the Foundation's peer-reviewed research program, because researchers themselves drive scientific innovation. Since the program's inception in 1999, The Alpha-1 Foundation has invested over **\$90 million** to support Alpha-1 research and programs at **128** institutions in North America, Europe, **South America**, the Middle East, and Australia, with a wide range of studies addressing the lung and liver disease of Alpha-1, as well as ethical, legal, and social issues that are especially important in a genetic condition such as Alpha-1.

The Foundation also owns the world's largest Alpha-1 Research Registry and DNA & Tissue Bank and has partnered with the NHLBI and LTRC to provide valuable resources for clinical and basic researchers. The Foundation also sponsors the Gordon L. Snider Critical Issues scientific conference series to promote scientific discourse.

Foundation-sponsored research has improved our understanding of the mechanisms underlying the clinical manifestations of Alpha-1, and has identified novel drug targets likely to lead to new therapies. The Foundation supports Alpha-1 research through its annual investigator-initiated grants program (in-cycle) complemented by an out-of-cycle program including Foundation-initiated requests for applications (RFA) or investigator-initiated applications to address issues deemed important but somewhat neglected by the research community.

## Research Grants

### In-cycle Investigator Initiated Grants

The Foundation offers grant awards in several categories. The first step in submitting a grant proposal is a letter of intent (LOI). If the LOI is deemed meritorious, we ask the investigator to submit a full application. Please check our website at [www.alpha1.org](http://www.alpha1.org) for updated application deadlines and instructions.

### Grant Categories

- Pilot and Feasibility Grant
  - Funding Level: Up to \$75,000
  - Period: Up to 1 year
- Postdoctoral Research Fellowship Grant
  - Funding Level: Up to \$75,000 per year
  - Period: Up to 2 years
- Research Grant
  - Funding Level: Up to \$100,000 per year
  - Period: Up to 2 years
- Ethical, Legal and Social Issues (ELSI) Grant
  - Funding Levels and Periods: ELSI projects may be submitted as any of the above categories
- Scientific Meeting Sponsorship Grant
  - Funding Level: Up to \$5,000

- Travel Grant
  - Funding Level: Up to \$1,000

### Out-of-cycle Grants

The purpose of this program is to support large, typically clinical grants that do not fit into the in-cycle grant program. Out-of-cycle grants can be Foundation-initiated RFAs or investigator-initiated proposals. The investigator should contact the Foundation before considering applying for an out-of-cycle application.

The Alpha-1 Foundation also offers funding opportunities through matching grants with various organizations. For more information on these and all our research grants, see Contact Information at the end of this brochure.

## Additional Resources

### Alpha-1 Research Registry

The Alpha-1 Research Registry is a confidential database of individuals with Alpha-1 and Alpha-1 carriers. It serves as a resource for clinical trials, surveys, and other scientific and medical data collection. For more information, please call 877-228-7321 ext. 252 .

