



Contact the Alpha-1 Association at 800-521-3025

### **NBC's Drama "ER" Highlights Alpha-1 Lung Disease Caused by Genetic Condition**

WASHINGTON, DC - November 8, 2002 - Last night's airing of NBC's prime time drama "ER" dramatically raised public awareness of a little known genetic disorder that leaves 100,000 Americans at risk of fatal lung and liver disease, and affects up to 20 million more as carriers.

The show focused on a young woman with Alpha-1 Antitrypsin Deficiency (Alpha-1) who was liver and lung affected and was allergic to Prolastin®, the only treatment available for Alpha-1. The dramatization of Alpha-1 resulted in a substantial increase in queries to the Alpha-1 Association from individuals concerned about symptoms indicative of this condition.

Raising the public's awareness of this often mis-diagnosed and certainly under diagnosed genetic condition is an important first step. The television show "ER" has gone a long way to helping raise this needed awareness.

Although 1 in 2500 Americans are thought to carry both Alpha-1 genes, putting them at high risk of progressive, incurable lung and liver disease, this disorder is often mis-diagnosed or under-diagnosed. Less than 10% of affected individuals have been properly identified. Early detection of Alpha-1 allows for preventative measures that can push back the onset of symptoms by years or even decades.

Preventative measures include avoidance of tobacco use and other exposure to smoke, minimizing exposure to lung pollutants, treating respiratory infections promptly and aggressively, maintaining an exercise routine, regular physician visits, moderate or no alcohol consumption, and proper nutrition.

## **Background**

Alpha-1 Antitrypsin Deficiency (Alpha-1) a genetic, inherited disorder that often results in progressive, incurable lung disease in adults and liver disease in adults and children. Diseases associated with Alpha-1 occur due to the Alpha-1 protein becoming stuck in the liver instead of getting out to the bloodstream. As it accumulates, it can cause cirrhosis and other liver disease. Since one of the primary functions of the Alpha-1 protein is to travel to the lungs and protect delicate tissue there, the absence of this protein can result in severe lung damage, often in the form of emphysema. There are an estimated 100,000 individuals with a severe deficiency of Alpha-1 who are at high risk of developing lung and liver disease, and 20 million more individuals who are affected as carriers.

## **About The Alpha-1 Association**

The Alpha-1 Association is a patient-driven, non-profit membership organization dedicated to identify those affected by Alpha-1 Antitrypsin Deficiency (Alpha-1) and to improve the quality of their lives through support, education, advocacy, and research. The Association offers comprehensive assistance to its members through support groups, a peer mentoring program, personal patient assistance, educational materials, strong public policy efforts, and a compassionate care program. Professional educational resources and information packets are offered to health care providers who care for patients affected by Alpha-1.

The Association, located in Washington DC, is a member of the various health related organizations including the Genetic Alliance, National Health Council National Society of Genetic Counselors, COPD Coalition, National Emphysema/COPD Association (NECA), National Society of Genetic Counselors and Research America.