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*Diagnosed Alpha-1
Antitrypsin deficient

+Diagnosed family member

October 26, 2014

The Honorable Governor Deval Patrick
Attn: Proclamation Office
State House
Boston, MA 02133

Dear Governor Patrick:

We respectfully request that you designate November as Alpha-1 Awareness Month in the state of Massachusetts. Alpha-1 Antitrypsin Deficiency (Alpha-1) is one of the most common serious hereditary disorders in the world and can result in life-threatening liver disease in children and adults or in lung disease in adults. An estimated 100,000 children and adults in the U.S. have the severe deficiency. An estimated 25 million in the U.S. carry a single deficient gene that causes Alpha-1 and may pass the gene on to their children.

Alpha-1 is widely under diagnosed and misdiagnosed. Fewer than 10% of those predicted to have Alpha-1 have been accurately diagnosed. It often takes an average of five doctors and seven years from the time symptoms first appear before proper diagnosis is made! However, Alpha-1 is easily detected using a simple test.

Alpha-1 is the most common known genetic risk factor for Chronic Obstructive Pulmonary Disease (COPD). Lung disease is the most frequent cause of disability and early death among affected persons, striking in the prime of life and a major reason for lung transplants.

Alpha-1 originates in the liver and can lead to liver failure at any time in life. It is the leading genetic cause of liver transplantation in children. Currently, the only treatment for liver disease of Alpha-1 is a liver transplant.

Please support our mission to bring awareness to our great state of Massachusetts by declaring November 2014 as Alpha-1 Awareness month. We will be conducting various awareness activities throughout the state to educate both the medical community and citizens on this serious and often fatal disease.

On behalf of the Alpha-1 Community, Alpha-1 Association (www.alpha1.org), Alpha-1 Foundation (www.alphaone.org), and AlphaNet (www.alphanet.org), I am asking that you declare November 2014 Alpha-1 Awareness Month.

Your consideration is very much appreciated.

Sincerely,

Sheila Favazza

Sheila Favazza
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The Alpha-1 Foundation is dedicated to providing the leadership and resources that will result in increased research, improved health, worldwide detection, and a cure for Alpha-1 Antitrypsin Deficiency. Alpha-1 is one of the most common hereditary disorders in the world and can result in life-threatening lung disease in adults and liver disease in children and adults.

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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.

The Alpha-1 Foundation is the leading national organization serving the Alpha-1 community and has been successful in building the infrastructure necessary to encourage Alpha-1 research worldwide and to support a community of all individuals affected by Alpha-1 Antitrypsin Deficiency (Alpha-1).

Programs are in place to ensure that individuals impacted by Alpha-1 have the support, education and advocacy required to improve their quality of life and maintain access to lifesaving therapies.

Areas of focus include:

- Providing support through its Support Network of 80 Support Groups, Patient Information Line and Genetic Counseling Program.
- Hosting national and regional education programs reaching more than 1000 Alphas, their families and healthcare professionals.
- Facilitating