

From: Marlene S. Erven [<mailto:mservern@alpha1.org>]
Sent: Tuesday, July 31, 2012 4:46 PM
To: Jeff Atwater
Subject: Sign-on Letter - Alpha-1 Association and Alpha-1 Foundation - Florida's State Health Exchange

Dear Mr. Atwater:

The Alpha-1 Association and Alpha-1 Foundation respectfully requests that the State Insurance Regulation Office, the Florida Department of Financial Services and the Essential Health Benefits Commission appointed by the Florida House, Senate and Governor Rick Scott take into consideration the attached recommendations to ensure that in the development of Florida's State Health Exchange that patients with rare diseases will be able to receive the care they need, in the time they need, and in the setting that is the most appropriate.

Sincerely,

Marlene Erven
Executive Director
Alpha-1 Association

John W. Walsh
President & CEO, Co-founder
Alpha-1 Foundation



July 30, 2012

Jeff Atwater
Chief Financial Officer
Florida Department of Financial Service
200 East Gaines Street, Tallahassee FL 32399

Dear Mr. Jeff Atwater:

The mission of the Alpha-1 Association is 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 mission of the Alpha-1 Foundation is to provide 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 a genetic (inherited) condition that may result in serious, chronic lung disease in adults and/or liver disease at any age.

We respectfully ask that in the development of Florida's State Exchange to please take into consideration and account for those patients who suffer from rare and chronic diseases. These individuals present unique challenges within the health care system, as many rare diseases require expensive, complex and specialized treatments. The patient protections below can be achieved through a balanced benefit design that offers affordable choices without compromising the quality or transparency of the benefit. They are:

- General Recognition of Rare Diseases
- Access to Specialists
- Access to Therapies
- Access to all Sites of Care
- Cost-Sharing
- Continuity of Care

The Alpha-1 Association and Alpha-1 Foundation also recommend that requirements for plans to use medical necessity criteria should be objective, clinically valid, and compatible with generally accepted principles of care. Furthermore, plan denials, based on lack of medical necessity, should explain in clear language the criteria used to make the determination. In addition, please make sure that the state navigators understand the unique needs of patients who suffer from rare and chronic conditions in order to provide them with information to fully understand their Quality Health Plan (QHP) options. They must have adequate training, be trusted sources of information, and adequately represent the populations that are most likely to enroll in the Exchange.

The Alpha-1 Association and Alpha-1 Foundation respectfully requests that the State Insurance Regulation Office, the Florida Department of Financial Services and the Essential Health Benefits Commission appointed by the Florida House, Senate and Governor Rick Scott take into consideration the above recommendations and ensure that patients with rare diseases will be able to receive the care they need, in the time they need, and in the setting that is the most appropriate.

Sincerely,

Marlene Erven

A handwritten signature in cursive script, appearing to read "Marlene Erven".

Executive Director
Alpha-1 Association

John W. Walsh

A handwritten signature in cursive script, appearing to read "John W. Walsh".

President & CEO, Co-founder
Alpha-1 Foundation