Alpha One Foundation

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Alfa Europe Position paper
Consultation regarding Community action on Health Services

Alpha-1 Antitrypsin Deficiency (Alpha-1) is one of the most common hereditary disorders. It has been identified in virtually all populations but is most common in individuals of Northern European and Iberian descent. It causes severe, life threatening lung damage in most patients, leading to emphysema. It can also cause life threatening liver damage in children and adults and liver cancer in adults.

Replacement and other therapies are available in some EU countries but it would not be practical for patients to travel any distance to receive their therapy on an ongoing basis. However, as the provision of therapy is not equally available in all EU countries we would make that case that all patients with this inherited chronic condition have whatever therapy is needed and prescribed made readily available to them.

On the other hand, the only real cure for this condition is either lung or liver transplantation and in very rare cases, both organs may need to be transplanted. We therefore encourage the commission to ensure that adequate transplant services are available in all member countries and where they are not available patients should be enabled to travel to receive them in other member countries.

We also propose that the commission encourage all member states to follow international best practice in the provision of medical services for all Alpha -1 patients regardless of their location or ability to pay.

We would further encourage the Commission to ensure equity of medical reimbursement among the member States. International best practice in reimbursement policies and practices needs to be attended to with urgency as it will have a huge effect on cross border treatment for patients.

Larry Warren, Chief Executive, Alpha One Foundation.
President, Alfa Europe.