PROFILE

Brendan Gallagher

LIVING WITH ALPHA-1 ANTITRYPSIN DEFICIENCY

"Access to treatment would be a real life-line for me and others with Alpha-1"

I received a diagnosis of Alpha-1, which is a genetic condition in 1996, and was referred to Beaumont Hospital Respiratory Consultant Professor Gerry McElvaney and his research team and have attended the Alpha-1 clinic since 2001. I have been affected to some degree by Alpha-1 for over 23 years but in the last 5 years have suffered diminished lung function.

I remain committed to the future - family, love for my wife, four children, their spouses and eight grandchildren. No other members of my family or siblings have symptoms of Alpha-1, COPD or Emphysema. I have been a non-smoker throughout my life as were my parents, but I had frequent exposure to passive smoking during teenage years and to environmental conditions such as diesel fumes in my working career.

I always loved cycling but I no longer cycle or use my car for even short commutes. I am fully dependent on portable oxygen and even walking short distances requires a break of approximately 2 minutes. Basic physical activities such as gardening, DIY, climbing the stairs are all reduced, and are carried out at a much slower pace. Through a DCU fitness research programme I joined a gym and do some basic exercises with a fitness coach. The gym combined with much-requested Grandad duties keep me busy. I have had to adjust to a different lifestyle and gain support and understanding from my family and friends when having to equip myself with a portable oxygen backpack and nasal tubes to partake in social or family activities.

There is a treatment for patients with Alpha-1, the cost of which is not covered by the HSE in Ireland. Access to treatment would be a real life-line for me and others with Alpha-1.

RARE DISEASE

About Alpha-1 Antitrypsin Deficiency (A-1)

Alpha-1 antitrypsin deficiency (AATD) is a rare genetic disorder where the body does not produce enough alpha-1 antitrypsin (AAT). AAT is an important protein which protects the lungs against cigarette smoke and bacterial infection. AAT deficiency can lead to lung, liver and skin disease. Most people present with chronic obstructive pulmonary disease (COPD). Over 3,000 individuals on the island of Ireland suffer from a severe form of AATD, and 1 in 25 individuals are carriers of an abnormal AAT variant. Unfortunately, AATD is under-diagnosed and long delays in diagnosis are common. The WHO recommends screening of people with COPD, poorly-controlled asthma, and liver disease. Advantages of an early diagnosis of AATD include increased lung and liver surveillance, family member testing, smoking cessation opportunities, and reduction of occupational and environmental exposures.