ANNUAL REPORT 2020

ALPHA-1 FOUNDATION IRELAND

MISSION STATEMENT

Alpha-1 Foundation Ireland is a charity dedicated to raising awareness, increasing diagnosis, promoting research, and improving the treatment of Alpha-1 Antitrypsin Deficiency (Alpha-1).

VISION

That everyone with Alpha-1 in Ireland is diagnosed and receives specialist care and treatment in a timely fashion.

CORE ACTIVITIES OF ALPHA-1 FOUNDATION IRELAND

STAFF OF THE ALPHA-1 FOUNDATION IRELAND

Ms Geraldine Kelly, CEO

Dr Tomás Carroll, Chief Scientist

PATRON

Michael D. Higgins, President of Ireland

TEL: 01-809 3871 **EMAIL:** alpha1@rcsi.ie **WEB:** www.alpha1.ie

Alpha-1 Foundation Ireland Charity Code: CHY22304

@Alpha1_Ireland Find us on Facebook

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1 Executive Summary

Every year presents challenges for our organisation but none like we were presented with in 2020. The year started out like every other with plans to increase the diagnosis of new patients through the screening programme, grow the registry database, increase our fundraising activities, expand our outreach programmes and as always focus on research projects. By the end of February 2020 we knew that Covid-19 would likely challenge the progress of some if not all of these activities. One thing we were sure of was that Alpha-1 patients would need additional support and advice during this very worrying time. Firstly, we developed a COVID-19 specific webpage, which clearly interpreted the HSE guidelines and offered advice to patients on what to do to protect themselves from this life threatening virus. With the support of Professor McElvaney and his medical team we setup a helpline which offered specific support to Alpha patients and their families. Our COVID-19 webpage received over 16,000 hits, and we handled well in excess of 400 calls and 150 email queries during the period March–September.

Due to the nature of this virus and its likely impact on a vulnerable group with respiratory issues, it was clear from the outset the importance of diagnosing as many patients as possible, and so our laboratory remained open and Tomás Carroll worked tirelessly to ensure that all bloods were analysed and results issued to hospitals and GP's quickly. During this period, we diagnosed 202 people with Alpha-1 of which 19 had the severest form, ZZ. We continue to strive to raise awareness of the condition and to encourage family testing with every new diagnosis. We encourage those diagnosed with Alpha-1 to discuss it with their family as knowledge is power and one thing we know through research is that some very simple lifestyle changes can have a hugely positive impact on those with the condition.

Education and outreach programmes are key to raising Alpha-1 awareness among medical professionals and the pandemic did not stop us from continuing this programme. Check out chapter 2 for updates. Our research projects continued and produced some very interesting papers some related to Covid-19 and others related to SZ type alpha-1 (more in chapters 6 & 7). Something which is always of interest to our patient group is the development of new treatments for Alpha-1 so it is encouraging to report that a number of clinical trials are about to begin during 2021.

We continued to partner and network with groups such as Health Research Charities Ireland, Irish Platform for Patient Organisations, Science and Industry (IPPOSI), Rare Disease Taskforce, European Organisation for Rare Diseases (EURORDIS) and COPD Support Ireland and benefit greatly from their experience.

We hosted a very successful conference in October 2019 and were very disappointed to have to postpone the event in 2020. We decided against a virtual conference as it might not be accessible to everybody so we look forward to seeing our regular attendees and some new faces during 2021.

We are extremely thankful for all fundraising and donations made to the Foundation over the last 12 months. All money is put to good use in our Alpha-1 screening programme, and many other activities benefiting Alphas and their families.

Our achievements are the result of a huge team effort by a small group of Foundation staff, and by research and medical teams. I wish to thank all my colleagues including Dr. Tomás Carroll, Professor Gerry McElvaney and his medical team, Dr. Alex Franciosi and Dr. Ciara Gough.

Geraldine Kelly
CEO, Alpha-1 Foundation Ireland

2 The National Alpha-1 Antitrypsin Deficiency Targeted Detection Programme – An Update

Alpha-1 antitrypsin deficiency (AATD or simply Alpha-1) can be diagnosed by a simple blood test but unfortunately remains hugely under-diagnosed. A diagnosis of Alpha-1 provides a unique opportunity for early medical intervention and can prevent or postpone lung disease in both the affected individual and their relatives. In May 2004, a national targeted detection programme for AATD was launched by Alpha-1 Foundation Ireland with funding from the HSE. As of November 2020 the programme has tested more than 20,500 people.

Who Should Be Tested for Alpha-1?

World Health Organisation (WHO), American Thoracic Society (ATS), and European Respiratory Society (ERS) guidelines advocate targeted detection programmes for AATD. These guidelines recommend targeted testing of specific patient groups, with a special focus on chronic obstructive pulmonary disease (COPD)(Table 2.1).

Table 2.1. *ATS/ERS recommendations for diagnostic testing for AATD (type A recommendations)*

Who Should Be Tested?
Adults with symptomatic emphysema or COPD (regardless of age or smoking history)
Adults with asthma with airflow obstruction that is incompletely reversible after aggressive treatment with bronchodilators
Asymptomatic individuals with persistent obstruction on pulmonary function tests with identifiable risk factors (e.g. cigarette smoking, occupational exposure)
Adults with necrotising panniculitis
Siblings of individuals with Alpha-1
Individuals with unexplained liver disease, including neonates, children, and adults, particularly the elderly

How Do We Test for Alpha-1?

There are two tests needed to correctly diagnose Alpha-1. The first test measures how much alpha-1 antitrypsin (or AAT) is in the blood. The second test looks at what type of AAT protein is present by a method called isoelectric focusing. This method identifies variants of AAT circulating in human blood, and is more commonly known as phenotyping (Figure 2.1). It is the most accurate method of diagnosing Alpha-1 and recognises the most common and also rare AAT variants.

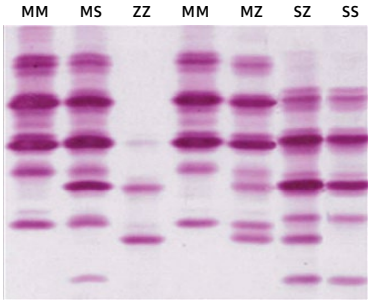
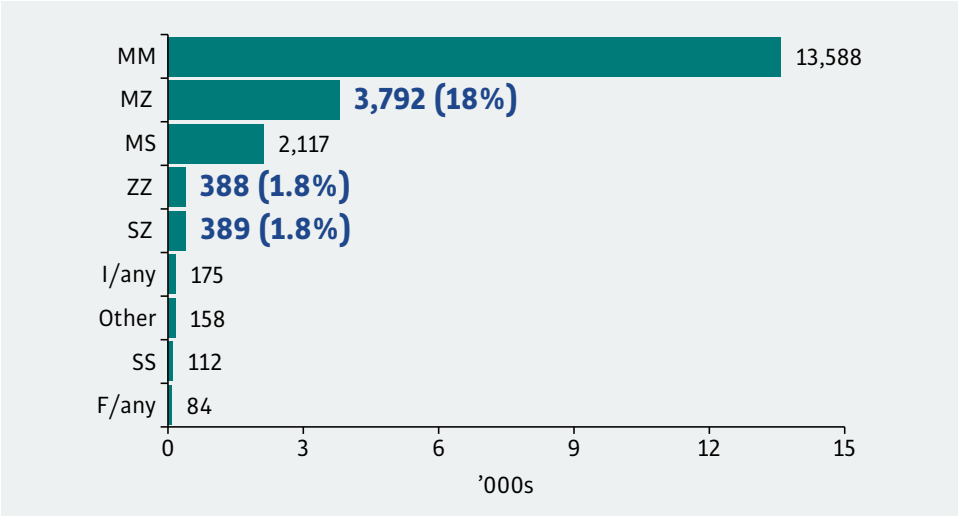


Figure 2.1. *Typical isoelectric focusing gel for AAT phenotype identification with the most common phenotypes included.*

What Have We Found in Ireland?

Since 2004 a total of 20,500 individuals with COPD, asthma, and liver disease, as well as first-degree relatives of people known to have AATD have been tested in a National Targeted Detection Programme.

Figure 2.2. *Results from the National AATD Targeted Detection Programme showing AAT phenotypes identified among the 20,500 individuals tested.*



A total of 388 ZZ (severe Alpha-1) individuals have been identified, as well as 389 SZ individuals, who are also at risk of developing lung (particularly if smoking) and liver disease Figures 2.2 and 2.3). In addition, a large number of other clinically significant phenotypes have been detected including 3,792 MZ, 24 IZ, and 12 FZ phenotypes. A number of very rare deficiency-causing AAT mutations have also been identified. These include M_{malton}, $M_{wurzburg}$, S_{munich}, and $Z_{bristol}$ and five different Null mutations ($Null_{bolton}$, $Null_{cork}$, $Null_{dublin}$, $Null_{porto}$ and $Null_{amersfoort}$). Two of these Null mutations had never been discovered before ($Null_{cork}$ and $Null_{dublin}$).

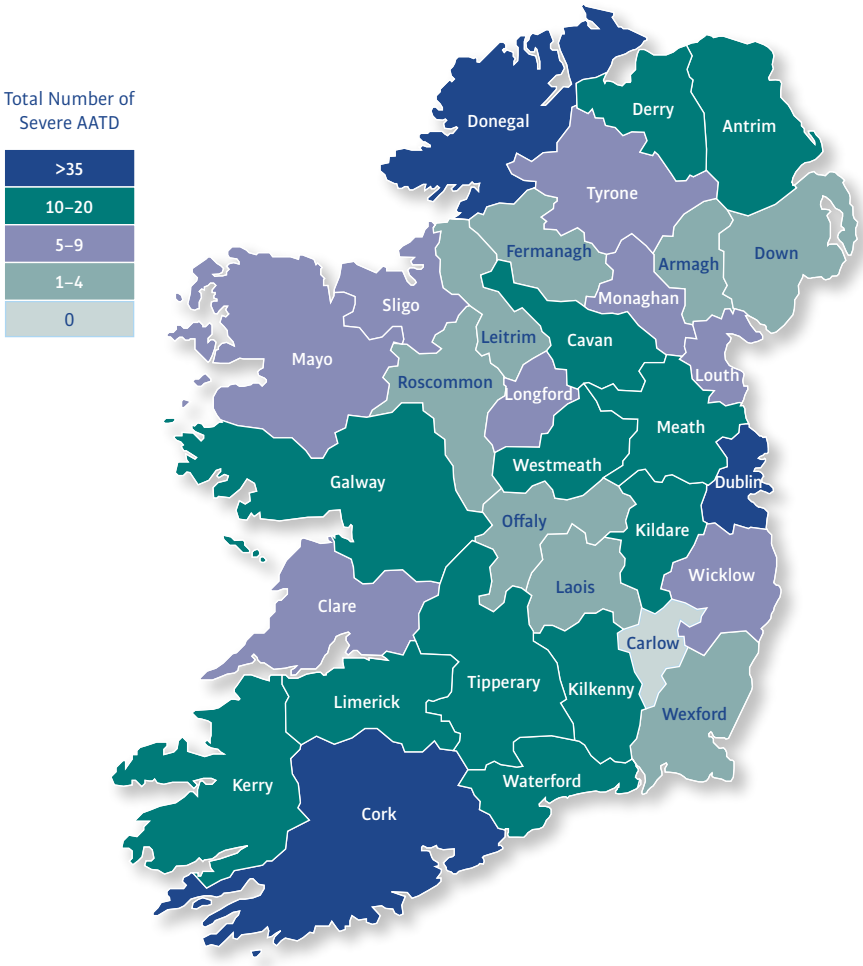
Figure 2.3. *Simple explanation of the most common AAT phenotypes in Ireland.*

AAT Phenotype/ AAT Genotype*	AAT Deficiency?	What does it mean?
MM	No	Does not have the disorder – has 2 normal copies of the AAT gene.
MS	Mild	No evidence of increased risk of lung or liver disease but does carry 1 altered AAT gene.
MZ	Moderate	Significantly increased risk of lung disease **in smokers**. Increased risk of liver disease.
SS	Moderate	Presumed increased risk of lung disease **in smokers**. No evidence for increased risk of liver disease.
SZ	Moderate	Significantly increased risk of lung disease **in smokers**. Increased risk of liver disease.
ZZ	Severe	Significantly increased risk of lung disease in **smokers and ever smokers**. Increased risk of liver disease.

The goal of the detection programme is to ensure people with Alpha-1 are correctly diagnosed and have the opportunity to receive expert medical care. Newly diagnosed individuals can be referred to the National Centre of Expertise for AATD in Beaumont

Hospital under the care of Professor Gerry McElvaney. A strong focus on family screening allows the identification of other family members with Alpha-1, which can help prevent or postpone the development of serious health problems in the wider family. Importantly, a correct diagnosis means people can benefit from lifestyle changes such as smoking cessation, closer medical surveillance by Alpha-1 experts, and the opportunity to enrol in clinical trials that test new treatments.

Figure 2.4. *Distribution of severe AATD cases detected to date (450 cases in total across 31 counties).*



Education and Outreach

In the past 12 months, and despite the COVID-19 pandemic, we have given in person and virtual presentations about Alpha-1 to a mixture of respiratory and laboratory teams in Cork, Limerick, and Wexford hospitals, to RCPI specialist respiratory trainees, and to 3rd year medical students in UCD. We hosted an Alpha-1 information table at the annual respiratory nurse conference in Portlaoise in February 2020. Defying the laws of physics we also attended the All Island Rare Disease Conference on the same day in Belfast. The aim of these presentations is to increase awareness of Alpha-1 among health professionals and to encourage testing. While respiratory (and liver) medical teams care for patient populations most at risk due to AATD, Immunology and Biochemistry departments in hospitals measure alpha-1 antitrypsin levels as a routine test during normal blood investigations.

Opportunities to increase the detection of AATD in the healthcare system in future include the roll-out of the National Medical Laboratory Information System (MedLIS) which is the new national IT system for laboratory medicine and the new national laboratory handbook which describes best practice in testing for AATD (*www.hse.ie/eng/about/who/cspd/ncps/pathology/resources/lab-testing-for-alpha-1-antitrypsn-antibodies.pdf*). Alpha-1 Foundation Ireland has made contributions to both initiatives with the goal of increasing the diagnosis of AATD.

3 The National Alpha-1 Antitrypsin Deficiency Registry

What is the registry?

The registry is a confidential database that stores relevant medical information of individuals diagnosed with alpha-1 antitrypsin deficiency (AATD). Results of tests that monitor lung and liver function such as blood tests, pulmonary function tests, CT scans of the chest and ultrasounds of the liver are obtained from medical charts, recorded in the registry and then updated at regular intervals.

What is the purpose?

The registry helps to deepen our knowledge and understanding of Alpha-1, improve clinical care for patients, and aid recruitment for clinical trials investigating new treatments for Alpha-1. The small numbers of people affected by a rare disease means that getting access to the right care, treatment and support can be difficult. Registries play an important role in filling gaps that exist in rare disease care.

Figure 3.1. *The Goals of the National Alpha-1 Registry.*

What are the key objectives of the Registry?

1. Increase our understanding of AATD (knowledge)
2. Inform and improve clinical care (care)
3. Provide early access to new treatments via clinical trials (treatment)

How can I enrol?

Individuals diagnosed with various forms of AATD are eligible to enrol in the registry. Enrolment is completely voluntary and an individual must provide their written informed consent prior to enrolment. A member of Alpha-1 Foundation Ireland will provide individuals with an information leaflet and answer any questions at the time of enrolment.

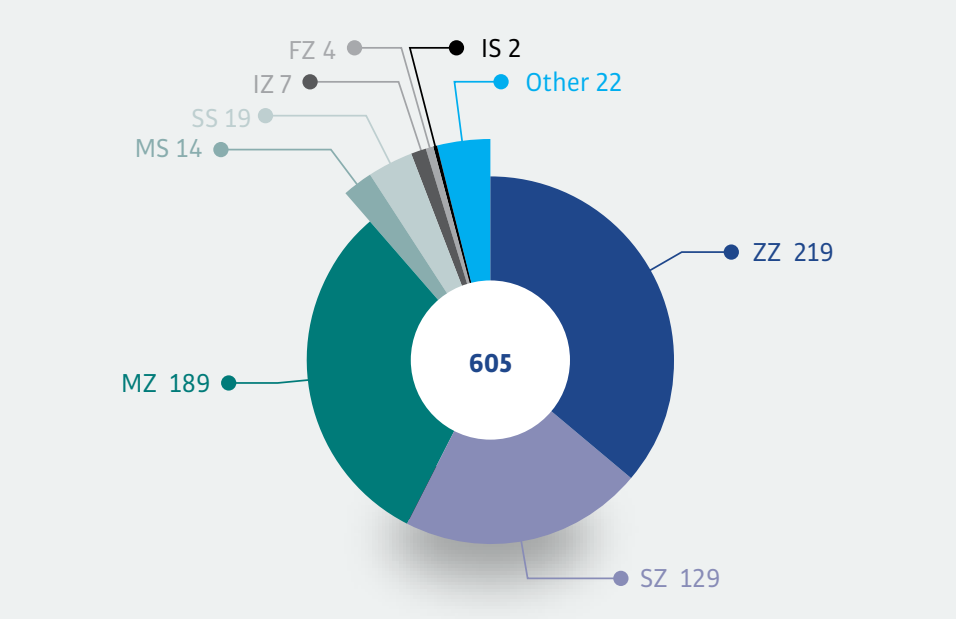
Questions?

If you or your family are interested in enrolling or have any questions about the registry please contact us on 01 809 3871. To read more about our registry visit *www.alpha1.ie/who-we-are/national-alpha-1-registry*.

Registry Redevelopment

During 2017 and 2018 the registry was re-developed with the help of Irish IT company OpenApp and the expert guidance of former colleague Margaret Molloy. Special mention also to Siobhán Lee who helped to expand the registry and ensure compliance with newer data protection laws. The new, improved National AATD Registry with enhanced user and security features and a family tree tool (Figure 3.2) was launched in summer 2018.

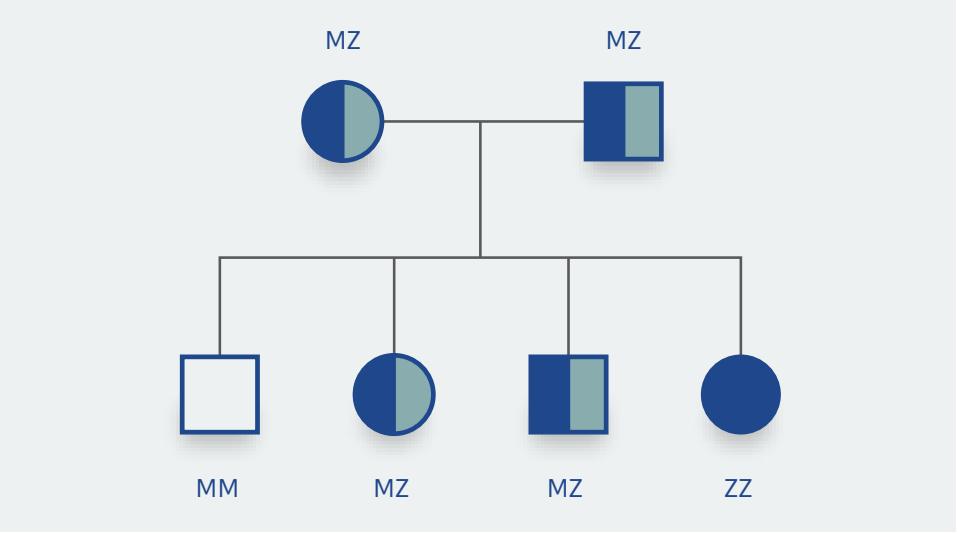
Figure 3.2. *Total number of individuals enrolled in the registry according to AATD phenotype (n = 605).*



Research publications using anonymous data from the registry have deepened our understanding of the risk factors and symptoms associated with the health problems caused by Alpha-1. For example, a recent study examined the risk of lung disease in people with SZ Alpha-1 [**"Clarifying the Risk of Lung Disease in SZ Alpha-1 Antitrypsin Deficiency." Franciosi et al., AJRCCM 2020**] and showed that those who never smoked were highly unlikely to develop any lung problems (for more see chapter 6).

This knowledge has led to greater focus on smoking cessation at the National Centre of Expertise for AATD as it is the number one intervention for people with Alpha-1. The findings once again highlight the importance of an early diagnosis of AATD so positive lifestyle choices (like stopping smoking) can be made.

Figure 3.3. *An example of the new family tree tool on the National AATD Registry.*



4 Recent Events

IPPOSI Virtual Seminar

In July our CEO Geraldine Kelly took part in a fascinating online seminar titled "Patients Re-imagining Healthcare." Organised by IPPOSI and with a virtual audience of almost 200, the panel discussed what the Irish healthcare system can learn from the COVID pandemic.

Cavan Fundraising Raffle

A big thank you to Stephen Smith for his generous donation to Alpha-1 Foundation Ireland in July after he held a raffle for an autographed Liverpool jersey. Stephen has been a fantastic supporter of the Foundation for many years. He has been raising awareness of organ donation by visiting schools in his native Cavan and has represented Ireland at the European Transplant Games, winning several medals.

Global Alpha-1 Leaders

Early July saw a podcast discussion among Alpha-1 leaders in several countries around the world, including Alpha-1 Foundation Ireland CEO Geraldine Kelly.

US Alpha-1 National Patient Conference 2020

Irish Alpha-1 research on MZ and SZ Alpha-1 was presented in June at the virtual US Alpha-1 National Conference. Attended by over 2,500 Alphas from the US, the research was carried out by the RCSI team at Beaumont Hospital but could not have happened without the help of almost 100 Irish families. The Alpha-1 community around the world is benefitting from this research and owes these families a huge thank you.

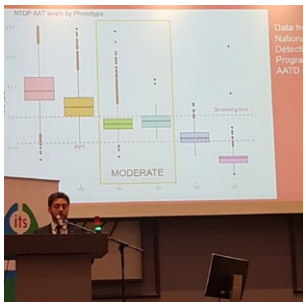
Alpha-1 Seminar to UCD Medicine Students

Alpha-1 Foundation Ireland visited UCD on January 28th to talk about Alpha-1 to the next generation of doctors.

Irish Thoracic Society Annual Scientific Meeting 2019

Alpha-1 Foundation Ireland hosted our usual educational stand at the Irish Thoracic Society scientific meeting in Galway in November 2019. Our aim is to raise awareness of Alpha-1 among the 450+ doctors, nurses, physios and scientists working in the field of respiratory medicine. We were delighted to welcome 2 Italian doctors, Dr. Stefania Marino from Palermo and Dr. Claudio Tirelli from Pavia. Both were visiting the Alpha-1 centre in RCSI Beaumont Hospital on a prestigious Maurizio Luisetti fellowship. The late Professor Maurizio Luisetti was a renowned Alpha-1 expert at the University of Pavia in Italy.

At the meeting in Galway, Dr. Alessandro Franciosi from RCSI presented his research on the risk of lung disease in SZ type Alpha-1 and was awarded the prize of best oral presentation. This important research could not have taken place without the help of 166 people from 44 Irish Alpha-1 families.



Irish Alpha-1 Study On Cover of Prestigious Journal in December

An Irish Alpha-1 article featured on the front cover of the December issue of The Lancet Respiratory Medicine, the top ranked respiratory journal in the world. The article is a simple guide to testing for Alpha-1 and was written by researchers from Alpha-1 Foundation Ireland and RCSI. The beautiful watercolour on the front cover was inspired by an image in the article and depicts common and rare AAT phenotypes.

Annual Alpha-1 Conference 2019

Our Annual Alpha-1 Conference held in October 2019 at the Marino Institute of Education in Dublin was a great success with a large audience enjoying a diverse mix of invited speakers. Special guests on the day were Miriam O'Day, CEO of the US Alpha-1 Foundation, and Niamh Kelly who gave her own unique family perspective and paid tribute to her dearly departed sister Marion.

5

Living with Alpha-1 – A Patient Perspective

Mr Brendan Gallagher

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.

44 NEWS 22 August 2017 | THE NATIONALIST

Naas man dismayed over decision not to fund life-changing drug

By Anna Hayes

A 71-YEAR-OLD Naas man, who is suffering from a genetic lung disease has voiced his disappointment over the Government decision not to fund a life-changing drug.

Brendan Gallagher was diagnosed with Alpha-1 antitrypsin deficiency in the early noughties, having noticed that he was becoming more and more breathless in carrying out his every day routine.

Diagnosis is often difficult and it took approximately six years for Mr Gallagher's conditions to be properly identified.

"I was very active and had a healthy lifestyle but I noticed that I was becoming very breathless and that has continued. I find I run out of breath and use oxygen on a daily basis to re-energise myself. There's no pain but the lack of oxygen feels distressing," he said.

He said that in his case the deformity was a genetic one. The illness is similar in nature to cystic fibrosis.

Mr Gallagher is part of the Alpha One Foundation and said that, despite the recent decision not to reimburse or fund the introduction of the life-changing drug, Respreeza, in Ireland, the debate is not over and they would continue to lobby the Government and health department.

He explained that 21 people are currently receiving the drug on a compassionate basis from the pharmaceutical company that developed it, but this was only on a month-by-month basis and there was now uncertainty over whether it would continue.

Mr Gallagher remarked: "It came down to economics and the National Centre for Pharmacoeconomics (NCPE) and HSE decided that the cost outweighed the effectiveness of the drug as a remedy. They are saying that they need further evidence of success. It can't cure the illness but it does slow down the process."

The 21 people who have been taking Respreeza for the last decade have said that their well-being improved dramatically but Mr Gallagher said that they had been in limbo for months and now they face even greater concerns.

He believed that there were about 100 people, outside of the group of 21, who would benefit from the drug and had been waiting in hope that it would be rolled out in Ireland. It is also believed that upwards of 250,000 people could be undiagnosed as Alpha-1 is a genetic ailment.

A number of other countries in the EU have already approved access to the drug.

"We have been campaigning for the last 18 months and this is a blow. Huge research was undertaken by Beaumont Hospital which has been widely acclaimed and proved useful in other countries where Respreeza is available."

He added that the cost of drugs in Ireland seemed to be wholly disproportionate to its cost in other European countries, despite the existence of a single market. He agreed that the decision, and reasons for it, showed that there was a price on life when it came to healthcare.

He added: "For me, all I can do is keep as healthy as I can. I have a fitness regime that I follow – light exercises that keep me in shape. DCU had, in association with Beaumont, been offering a specialised fitness programme which was a help. But these things are only beneficial to a certain extent – we need Respreeza."

Brendan Gallagher from Naas with Deputy Bernard Durkan outside Leinster House

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 lung disease caused by Alpha-1.

This article first appeared in the "An Easy Guide to Rare Diseases in Ireland" published in February 2020. Thanks to HRCI, IPPOSI, and Rare Disease Ireland for permission to reproduce.

6 SZ Alpha-1 – What's New?

Two new research studies exploring risk of lung disease in SZ type Alpha-1 were published in 2020.

1. The SZ Registry Study

The SZ registry study, published in "Thorax" in September 2020, analysed the data of 486 people with different types of AATD who are currently participating in the Irish national AATD registry. The data analysed included age, gender, height, weight, smoking history, reason for diagnosis, breathing test results and CT scan findings. The MZ, SZ, and ZZ groups were then compared.

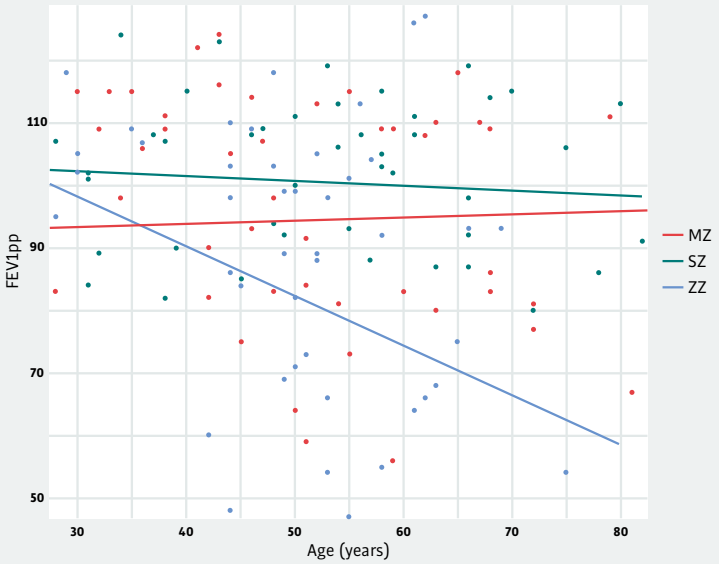


Figure 6.1. *Never smoker lung function in MZ, SZ, and ZZ groups (as measured by FEV1 % predicted or "pp") versus age (years).*

Key Findings:

- Never-smoking MZ and SZ groups demonstrated normal lung function, and no participants from either MZ or SZ group had emphysema on CT scan (see Figure 6.1).
- Even when MZ and SZ groups with a history of smoking were compared, no difference in lung function was observed.
- The results of this national registry analysis suggest that SZ AATD poses a risk for the lung disease chronic obstructive pulmonary disease (COPD) which is similar to MZ, and not the ZZ genotype.

2. The SZ Family study

A family-based study of 44 Irish families containing at least 1 person who was SZ (see Figure 6.2 for study design) took place between 2016 and 2019. This study was led by Dr. Alex Franciosi and was published in the prestigious American Journal of Respiratory and Critical Care Medicine in July 2020.

This was the first study to compare a large number of SZ individuals with a "normal-risk" group of MM and MS relatives recruited from the same families. The family approach is a powerful method of answering research questions because subjects within the same families have experienced many of the same environmental conditions in childhood and adulthood (for example parental cigarette smoke), particularly so when comparing siblings from the same family.

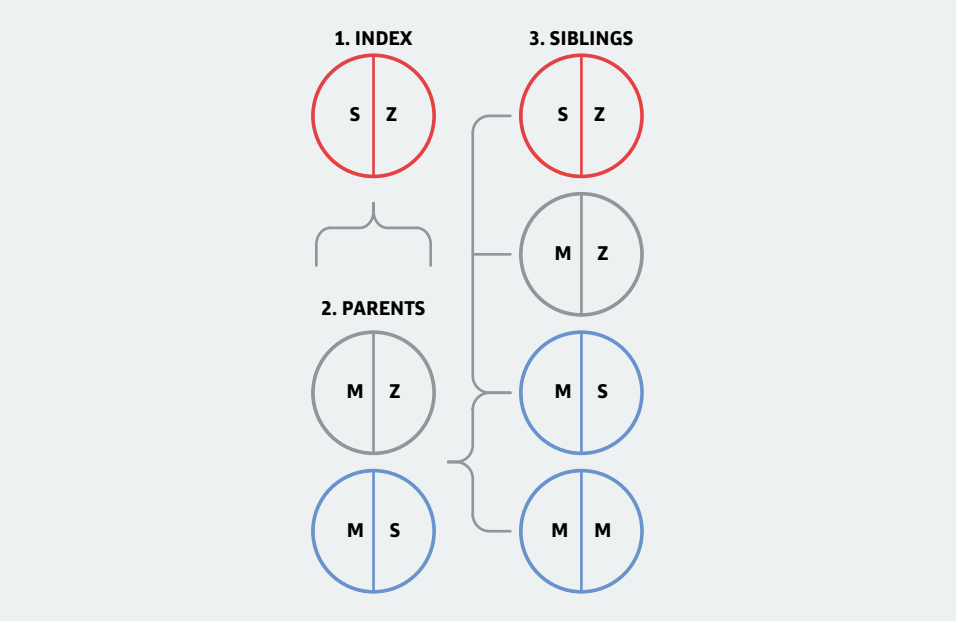


Figure 6.2. *SZ index cases (1) were invited to take part. Parents (2) and siblings (3) of the index SZ cases were next invited to take part and following testing for Alpha-1 are predicted to include SZ (red) and MS/MM (blue, control or "normal risk") participants.*

Sophisticated statistical tools were used to analyse the data with the help of collaborators Edwin Silverman, Craig Hersh, and Brian Hobbs of Brigham and Women's Hospital in Boston, USA. There were 166 participants in total who all received breathing and blood tests along with a questionnaire.

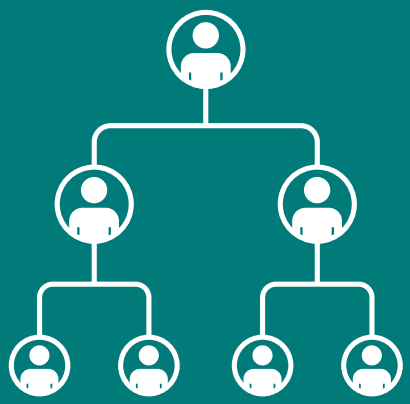
Key Findings:

- SZ never-smokers demonstrated no increased risk of COPD when compared to their never smoking MM and MS relatives.
- Smoking combines with the SZ genotype to significantly increase the severity of COPD when compared to ever smoking MM and MS relatives. This means that smoking cigarettes (or long periods of exposure to workplace chemicals, dusts and fumes) is required before significant lung disease will develop.
- A history of smoking alone is not associated with greater lung function decline in SZ-AATD, suggesting that stopping smoking prevents lung disease from getting worse.
- People with MS genotype of Alpha-1 were no different to people with 2 normal copies of their Alpha-1 gene (MM). This is reassuring for many people who are MS (1 in 10 in Ireland are MS) as this means there is no evidence for any increased risk of lung disease due to this type. This observation has been confirmed in other large studies outside of Ireland.

7

Latest Research Developments in Alpha-1

New ZZ Family Study



A new all island study exploring the risk of lung disease in families containing people with ZZ AATD will begin in the coming year. This follows on from our 2 previous successful studies of families containing either MZ or SZ alpha-1 antitrypsin deficiency (AATD) members. We know from how AATD is inherited that if a person in a family has ZZ AATD, the chances of other siblings also having ZZ AATD are quite high. Taking part will involve breathing tests, questionnaires, and some blood tests.

In this study we hope clarify to what extent lung disease is present in the siblings, parents and children of those with ZZ AATD, who have yet to be diagnosed or present themselves to their doctor because of lung problems. This important question remains unanswered and we hope to clarify the hidden burden of ZZ AATD in Ireland among families.

If you have been diagnosed with ZZ AATD and think your family would be suitable to take part in the study, please email *danieldfraughen@rcsi.ie* or *alpha1@rcsi.ie* to find out more.

New Clinical Trials for Severe Alpha-1

There are currently a number of promising Clinical Trials looking at new treatments for people with AATD. The first such study, sponsored by Vertex, with Professor McElvaney as the Principal Investigator at Beaumont Hospital, will be open for recruitment starting December 2020. Eligible participants will be people who are ZZ Alpha-1, who are not currently on augmentation therapy. The study will be investigating an oral medication for its safety and efficacy in this particular group of patients. This is a Phase 2 (early development) study and will potentially lay the groundwork for many other studies in this area in the future.

There are also other studies, one looking at inhaled medications which will be getting started in early 2021 and another observational study (EARCO), which will be gathering information on the natural history of people with AATD across Europe.

If you would like to find out more about these and future studies, you can contact Ann Collins, Clinical Research Coordinator at *annmcollins@rcsi.ie* or by calling 01-809 3862.

Irish Research Related to Alpha-1 Published in 2020

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4. Strnad P, McElvaney NG, Lomas DA. Alpha-1 Antitrypsin Deficiency. N Engl J Med. 2020 Apr 9;382(15):1443-1455.

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Financial Report

Alpha-1 Foundation Ireland
(A Company Limited by Guarantee and not having Share Capital)
Income and Expenditure year ended 31 December 2019

TURNOVER	
Northern Area HSE	119,565
Northern Area HSE – Therapy Administration Grant	80,000
Donations	20,354
Other Funding	75
Health Research Board - MRCG/HRB Grant	39,618
	259,612
EXPENDITURE	
Wages and salaries	(65,395)
Lab Costs	(6,534)
Point Of Care Health Services Ltd	(10,915)
Conference costs	(1,823)
Printing, postage and stationery	(2,790)
Computer costs & System maintenance	(19,525)
Travel - Education & Outreach Programme	(1,367)
Research Costs	(47,867)
Accountancy fees	(6,212)
Bank charges	(50)
General expenses	(4)
Subscriptions	(7,999)
	(170,473)
OPERATING SURPLUS	89,139

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We would like to thank the following:

- Margaret Molloy, Siobhán Lee, and Dr. Laura Fee, three valued former colleagues in Alpha-1 Foundation Ireland who each made huge contributions to our mission
- Orla Cahalane, Emma Pentony, Ella Howard, Bríd Holohan, Dr. Bill Tormey and the Beaumont Hospital Chemical Pathology Department for their continued support and assistance
- Angela McBride and colleagues from the Alpha-1 Foundation (USA) for their continued support
- Dr. Ilaria Ferrarotti and Dr. Stefania Ottaviani, Centre for Diagnosis of Inherited Alpha-1 Antitrypsin Deficiency, University of Pavia, Italy
- Louise Clarke and colleagues in the Pulmonary Function Laboratory in Beaumont Hospital
- Nour Keshk, RCSI medical student who carried out a research project with Alpha-1 Foundation Ireland in early 2020
- Health Research Charities Ireland (HRCI), the Irish Platform for Patients' Organisations, Science & Industry (IPPOSI), the Irish Lung Health Alliance, and the Irish Thoracic Society (ITS)
- President Michael D. Higgins for his continued support as patron of Alpha-1 Foundation Ireland
- A special thank you to everyone who took part in or organised awareness and fundraising events throughout the year

We would also like to thank the Department of Health and Children and the Health Service Executive for their continued financial support.

We would also like to acknowledge the participation of the following hospitals:

- Beaumont Hospital
- Blackrock Clinic
- Bon Secours Hospital Tralee
- Bon Secours Hospital Dublin
- Cavan General Hospital
- Children's University Hospital, Temple Street, Dublin
- Coombe Women and Infants University Hospital
- Cork University Hospital
- James Connolly Memorial Hospital Blanchardstown
- Kerry General Hospital
- Letterkenny University Hospital
- Mater Misericordiae University Hospital, Dublin
- Mayo General Hospital
- Midland Regional Hospitals: Tullamore, Mullingar and Portlaoise
- Naas General Hospital
- Our Lady's Children's Hospital, Crumlin
- Our Lady of Lourdes Hospital, Drogheda
- Our Lady's Hospital, Navan
- Peamount Hospital, Dublin
- Roscommon County Hospital
- Rotunda Hospital, Dublin
- Sligo University Hospital
- St. James's Hospital, Dublin
- St. Luke's General Hospital Carlow/Kilkenny
- St. Vincent's University Hospital, Dublin
- South Tipperary General Hospital, Clonmel
- Tallaght University Hospital
- University Hospital Galway
- University Hospital Limerick
- University Hospital Waterford
- Wexford General Hospital


3,000 ZZ
12,000 SZ
250,000 MZ

TEL: 01-809 3871 **EMAIL:** alpha1@rcsi.ie **WEB:** www.alpha1.ie

Alpha-1 Foundation Ireland Charity Code: CHY22304

@Alpha1_Ireland

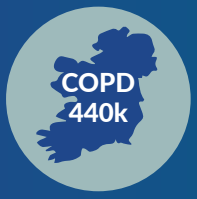
Find us on Facebook

Alpha-1 is the most common genetic cause of COPD

Smokers who carry just a single defective Alpha-1 gene have

10 fold increased risk of developing lung disease like COPD

1 in 25 people in Ireland carry the faulty Z Alpha-1 gene



The Irish Thoracic Society estimates approximately

440,000 people have COPD in Ireland

20,500+ individuals tested for Alpha-1 to date in the National Targeted Detection Programme

800+ people attending National Centre of Expertise for Alpha-1 at Beaumont Hospital

600+ people enrolled on the National Alpha-1 Registry