ANNUAL REPORT 2021

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 ALPHA-1 FOUNDATION IRELAND

Ms Geraldine Kelly, CEO

Dr Tomás Carroll, Chief Scientist

Ronan Heeney, Medical 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

ANNUAL REPORT 2021

ALPHA-1 FOUNDATION IRELAND

CONTENTS

1 Executive Summary

The COVID-19 pandemic meant 2021 continued to be a very difficult and worrying year for our patients and their families. We certainly didn't anticipate that the pandemic would continue through 2021 and beyond. A strong and successful vaccine programme offered protection to patients and our ability to get Alpha-1 patients elevated to Category 4 (High Risk) in the vaccination programme was a very positive step. During 2021 we continued to engage with the HSE ensuring patients received booster shots as quickly as they became available.

Like most organisations we were restricted to online events, however we successfully contributed to and participated in a number of global online conferences in collaboration with the US Alpha-1 Foundation. In February 2021 as part of a Global Advocacy Training Webinar I presented an overview of the response and support offered to our patients by both Alpha-1 Foundation Ireland and the Beaumont Alpha-1 medical team during the early days of the pandemic. This targeted support proved to be extremely beneficial to our patient group. In addition as part of the Global Patient Congress which took place in October 2021 myself, Dr. Tomás Carroll and Daniel Grimm an Alphanet Coordinator and Alpha-1 patient participated in a panel discussion around the importance of Clinical Trials. We tried to take some of the uncertainty and confusion out of this very important topic. For more on clinical trials see chapter 6 of this report.

RCSI joined the HRB PPI (Patient and Public Involvement) Ignite network whose focus is to enhance patient and public involvement in research. RCSI will co-lead a work package that seeks to embed PPI locally and nationally; supporting existing successful initiatives and looking to develop new, innovative forms of PPI implementation. I am delighted to say that we have been invited to partner with the PPI (Public Patient Involvement) Office in the RCSI.

Many charities experienced a reduction in fundraising activities during 2020 and 2021. We are delighted to confirm that our donation revenue increased by 36% over this period. As always we are so grateful for the help we receive from our patients. Donations made it possible for us to replace and upgrade our laboratory machine, a key piece of equipment vital for the correct diagnosis of Alpha-1. Funding is also helping us to further develop our patient registry which is a vital tool used in research projects and clinical trials.

The theme for this annual report is "The Alpha-1 journey from baby to adult" and our plan for 2022 is to work with Crumlin Hospital to explore the development of a clearer pathway for children with Alpha-1 as they move from paediatric into adult care.

None of this would be possible without the excellent contribution and support of our patients and their families and of my colleagues Dr. Tomás Carroll and recently recruited junior scientist Ronan Heeney. I would also like to thank the medical team working under Professor Gerry McElvaney, in particular Dr. Daniel Fraughen, Dr. Malcolm Herron, and Dr. Lameese Alhaddah.

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 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. By the end of December 2021 the programme had tested more than 21,500 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 certain patient groups, with a special focus on chronic obstructive pulmonary disease (COPD)(Table 2.1).

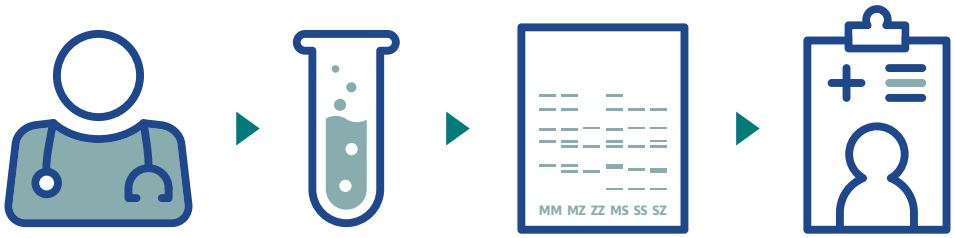


Figure 2.1. *Simple testing process for Alpha-1 involving a visit to a GP, blood sample, laboratory test and a report.*

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?

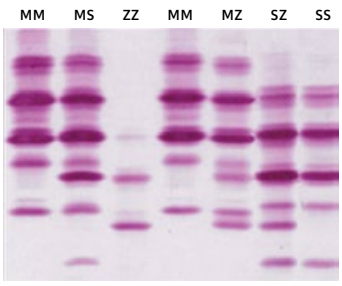


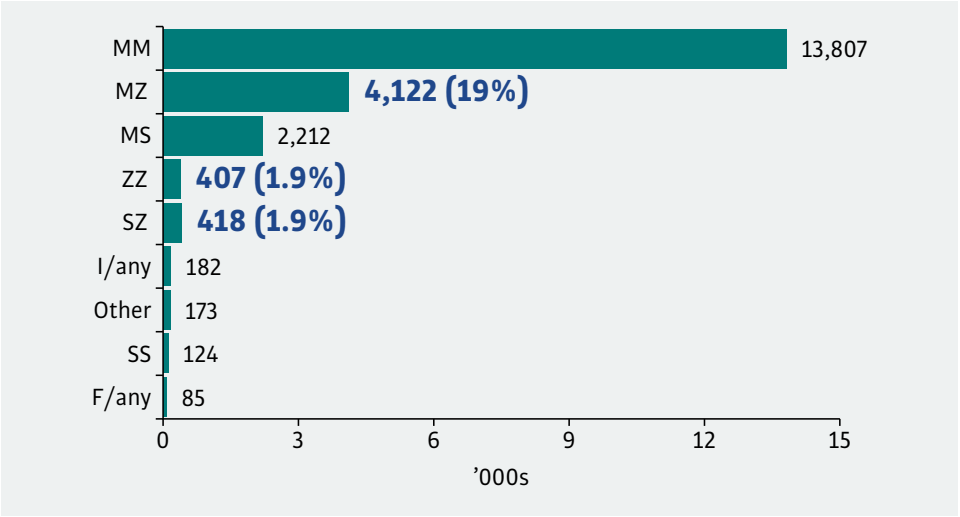
Figure 2.2. *Typical isoelectric focusing gel for AAT phenotype identification with the most common phenotypes included.*

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 2.2). It is the most accurate method of diagnosing Alpha-1 and recognises common and also rare AAT variants.

What Have We Found in Ireland?

Since 2004, more than 21,500 individuals with COPD, asthma, and liver disease, as well as first-degree relatives of people with AATD have been tested in a National Targeted Detection Programme.

Figure 2.3. *Results from the National AATD Targeted Detection Programme showing AAT phenotypes identified among more than 21,500 individuals tested.*



A total of 407 ZZ (severe Alpha-1) individuals have been identified, as well as 418 SZ individuals, who are also at risk of developing lung (particularly if smoking) and liver disease (Figure 2.3). In addition, a large number of other clinically significant phenotypes have been detected including 4,122 MZ, 25 IZ, and 12 FZ. A number of rare and very rare deficiency-causing AAT mutations have also been identified. These include $M_{heerlen}$, M_{malton}, $M_{wurzburg}$, S_{munich}, and $Z_{bristol}$ and six different Null mutations ($Null_{bolton}$, $Null_{cork}$, $Null_{dublin}$, $Null_{lisbon}$, $Null_{porto}$ and $Null_{amersfoort}$). Two of this sextet were discovered for the first time and received Irish names ($Null_{cork}$ and $Null_{dublin}$)

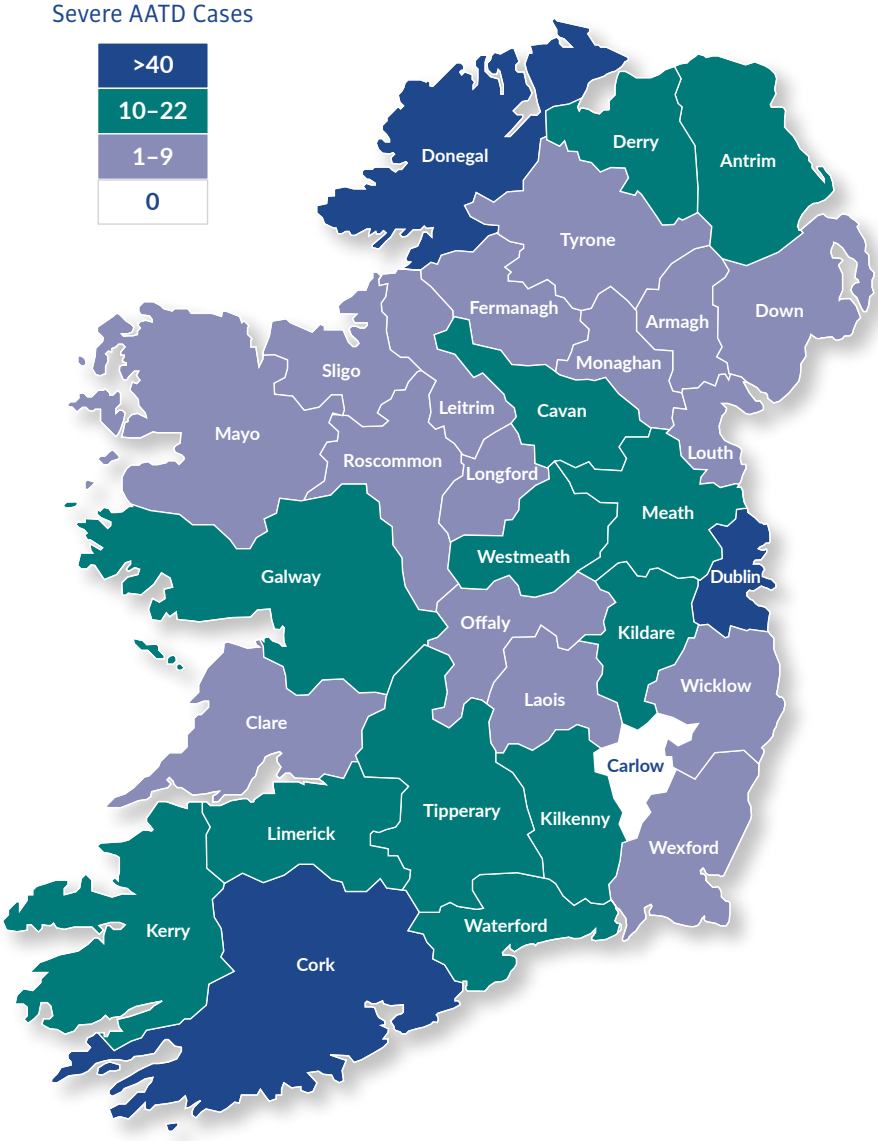
Table 2.2. *Simple explanation of the most common AAT phenotypes.*

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 national detection programme is to ensure people with Alpha-1 are correctly diagnosed and have the opportunity to receive expert medical care, advice, and support. 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 can identify 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, specialist medical care from 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 (465 cases in total across 31 counties).*



How Can We Increase Testing for Alpha-1?

In 2021 we held in person or virtual presentations about Alpha-1 to a mixture of respiratory and laboratory teams in Mater, Crumlin, Rotunda, and Tallaght hospitals, to 3rd year medical students in UCD, and to Balally and Bray COPD Support Groups. We also spoke at the Irish Society of Human Genetics conference and at the ANÁIL respiratory nurse conference. 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 patients most at risk due to AATD, hospital laboratories (Immunology and Biochemistry) measure alpha-1 antitrypsin levels during normal blood investigations.

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, breathing tests, CT scans of the lungs and ultrasound or FibroScan of the liver are 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 increase recruitment for clinical trials investigating new treatments for Alpha-1. The small number of people affected by a rare condition like Alpha-1 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, particularly in Ireland which has no electronic healthcare record.

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.

If I have questions?

If you or your family are interested in enrolling or have any questions about the registry please contact us on 01 8093871. To learn more about our registry visit *www.alpha1.ie/irish-alpha-1-registry/*.

Registry Update and Future Plans

At the end of 2021 a total of 640 people were taking part in the National AATD Registry (Figure 3.2) and this number is growing all the time. In 2022 we hope to improve and expand the registry with the help of Irish healthcare IT company OpenApp. Enhancements will include new sections to capture e-cigarettes and vaping use.

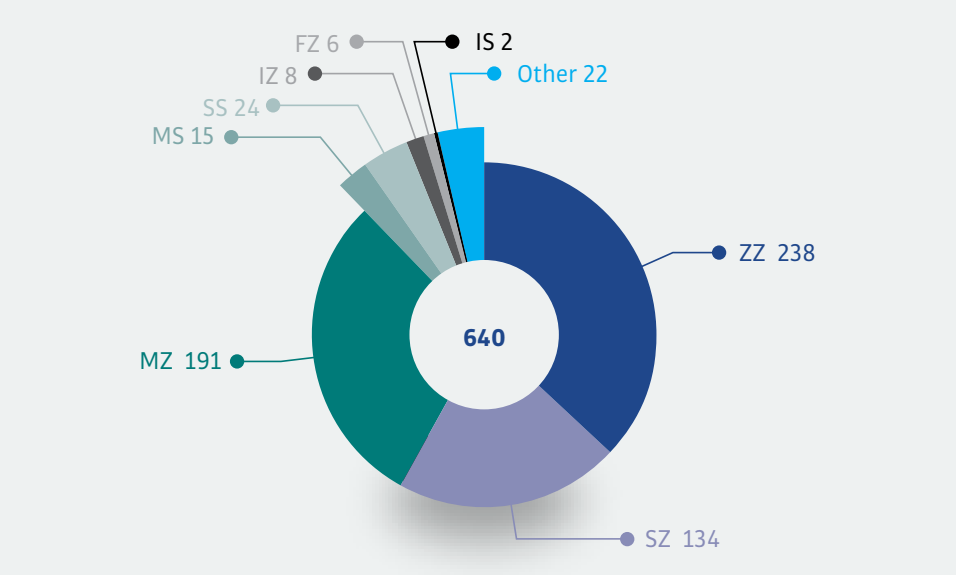


Figure 3.2. *Total number of individuals enrolled in the registry according to AATD phenotype (n = 640).*

Research using anonymous data from the registry has improved our understanding of the risk factors and symptoms associated with the health problems caused by Alpha-1. For example, a recent study examined cigarette smoking trends in people with Alpha-1 enrolled in the registry. The study [**Alpha-1 Antitrypsin Deficiency and Tobacco Smoking: Exploring Risk Factors and Smoking Cessation in a Registry Population, Franciosi et al, Journal of COPD, 2021**] showed that smokers were highly motivated to stop smoking after finding out they had Alpha-1. In addition, people with 1 or 2 parents who smoked were more likely to become smokers themselves (see Figure 3.3).

This important knowledge has led to a greater focus on smoking cessation at the National Centre of Expertise for AATD to prevent lung disease in current and future generations within Alpha-1 families. The findings once again highlight the importance of an early diagnosis of all types of AATD so positive lifestyle choices (like stopping smoking) can be made.

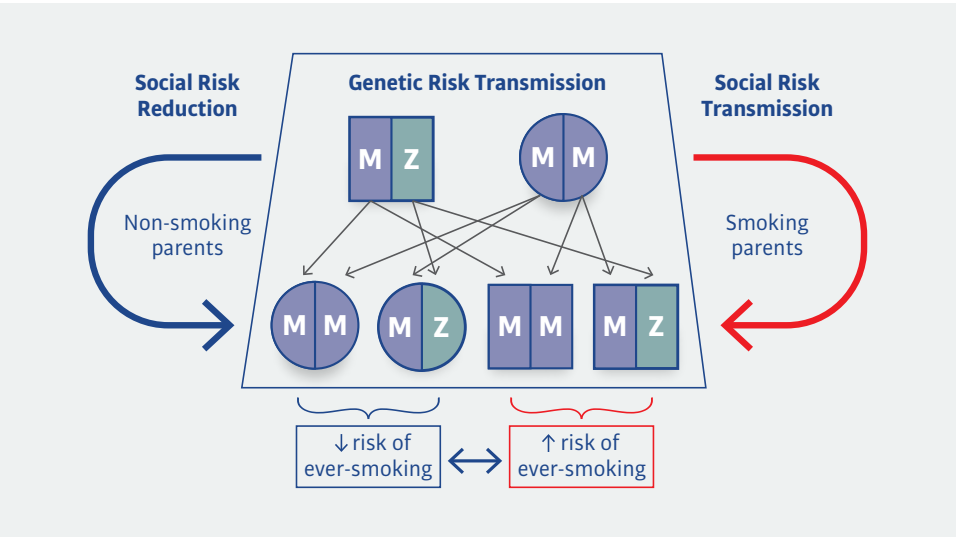


Figure 3.3. *An example of the new knowledge generated from a smoking survey of people taking part in the National AATD Registry. The diagram shows how 2 risk factors are inherited in families with a parent who smokes; the genetic risk of Alpha-1 (Z type) and the habit of smoking.*

4 The Alpha-1 Journey from Baby to Adult – A Parent's Perspective

Our son, Seán, was diagnosed with Alpha-1 Antitrypsin Deficiency when he was 6 weeks old. Seán was born a healthy baby, but he struggled to put on weight. Initially we thought he wasn't getting enough milk, as I was breast feeding. So we switched to baby formula and tried two different brands. But when he was five weeks old, Seán weighed just over six pounds – he still looked like a new born baby. At this point, we decided to bring him into University Hospital Limerick.

The blood tests showed that Seán's bilirubin levels were extremely high. The results indicated that the liver was not working at the "normal" level. Limerick transferred us to Crumlin hospital. A liver biopsy was booked for the following week. Some theories were discussed about what was happening and staff prepared us that Seán may even need a liver transplant in a few years' time. A social worker was assigned to us – if the biopsy showed that the liver was failing, a procedure would be required in a hospital in London when Seán was eight weeks old and we needed to fast track a passport for Seán.

In the meantime, my aunt in London contacted me and told me that Alpha-1 was in our family – her grandson had been diagnosed with Alpha-1 10 years previously. My aunt knew that she herself had Alpha-1 (SZ type) and she said it was possible that my father and I were also carriers (this later proved to be correct; we carry the MZ type). When we told the doctors about this link, they immediately tested Seán for the gene.

It was confirmed that Seán was ZZ within a few days – we were actually thankful that we had a diagnosis and now a plan of action! We were also very glad that we didn't need the liver biopsy or indeed a flight to London. We started a specialised baby formula and he started to steadily put on weight. We were discharged from Crumlin hospital after 10 days.

Seán is now almost three years old and he is a thriving happy boy. He was on the specialised baby formula until he was six months old but apart from that, his diet is like any other three-year-old. He is developing very well and his weight and height is well above average.

We now have a yearly check-up in Crumlin Hospital (liver scan & bloods), but he is doing extremely well. When we initially discovered that Seán had Alpha-1, we were of course terrified of this diagnosis. However, we are now relieved that we know of the importance of regular health checks – and especially of the importance of not smoking or being exposed to passive smoking, at this early stage in Sean's life. With early detection, Seán will hopefully have a long, healthy and happy life.

5 Recent Events

Marathon Challenge

Family and friends of one of the original Alpha-1 warriors Josephine McGuirk completed a unique marathon challenge in February. The goal was to raise awareness of Alpha-1 and to fundraise for Alpha-1 Foundation Ireland.

The challenge took place in short segments across Dublin, Meath and Kildare because of COVID-19 public health measures. The Warriors surpassed their original 5k target, raising a staggering €11,800. A huge thank you to the McGuirk family, friends and everyone who supported them. Thanks also to BOC Gases Ireland for their generous donation.

Award for Alpha-1 Researcher

In February, the Health Research Board (HRB) announced Gerry McElvaney, Alpha-1 specialist at Beaumont Hospital and Professor of Medicine at RCSI, as winner of the HRB Impact Award 2021. Congratulations to Professor McElvaney on winning a prestigious award which recognises over 35 years of research into alpha-1 antitrypsin deficiency, as well as cystic fibrosis and COPD.

Alpha-1 on the Radio

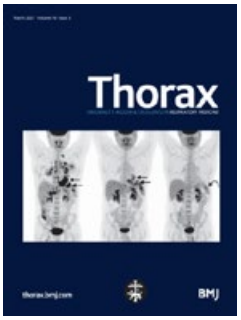
Geraldine Kelly, CEO Alpha-1 Foundation Ireland featured on radio station Near FM in February to talk about the signs and symptoms of Alpha-1, and how easy it is to get tested.

Irish Research into Smoking Cessation in Alpha-1

More Irish research published in the Journal of COPD in February showed smoking cessation is increased in people diagnosed with Alpha-1. The study found that people diagnosed with Alpha-1 are more likely to stop smoking once informed about the risks to their lung health. It is a simple but effective message which will hopefully lead to more testing for Alpha-1 and more people getting a correct diagnosis.

COVID-19 Information Webinar

Alpha-1 Global hosted a Patient Advocacy webinar at the end of February. The webinar provided tips on how to conduct a successful advocacy campaign for Alpha-1 community members around the world. It featured a presentation from Geraldine Kelly, CEO of Alpha-1 Foundation Ireland who discussed the impact of COVID on the Irish Alpha-1 community.



Irish Alpha-1 Research Published

New Irish Alpha-1 research published in the prestigious journal Thorax in March 2021. The research shows that people with SZ type Alpha-1 appear quite similar to MZ when assessing the risk of lung disease. This means that cigarette smoke is needed for lung damage to occur in both MZ and SZ type. Important enough to feature in the highlights section, the research was also discussed in an editorial. A huge thank you to everyone who takes part in the National Alpha-1 Registry. Without your help, studies like this would not be possible.

Irish Independent Article on Alpha-1

A fantastic article on Alpha-1 appeared in the Health & Living section of the Irish Independent in March. Thank you to the Colfer family for sharing their story and to Regina Lavelle the journalist.

Educational Visit to Mater Hospital

Alpha-1 Foundation Ireland visited the Mater Hospital in Dublin in April to talk about all things Alpha-1. Visits to hospitals like this are an important way to raise awareness and stress the importance of testing for Alpha-1 in people with COPD.

RTÉ RAIDIÓ NA GAELTACHTA

Alpha-1 on the Radio i nGaeilge

Rinne Tomás Carroll agallamh beag i Meitheamh ar RTE Radió na Gaeltachta faoin ráta ard Alpha-1 agus an galar COPD i nDún na nGall. Buíochas le Michelle Nic Grianna agus Dónall MacRuairí ón clár Barrscéalta don deis seo.

Conference Presentations on Alpha-1

Alpha-1 Foundation Ireland was busy in September with two conference presentations on the same day. In the morning we spoke at the 8th Annual Respiratory Nursing conference and in the afternoon we presented results from the national Alpha-1 targeted detection programme at the Irish Society of Human Genetics annual meeting. The aim of both presentations was to raise awareness of Alpha-1 among healthcare professionals and scientists.

The Global Alpha-1 Patient Congress

The Global Alpha-1 Patient Congress took place in October. Guests from around the world attended the virtual meeting with a live translation feature converting presentations into 20 languages. Geraldine Kelly and Tomás Carroll from Alpha-1 Foundation Ireland took part in a panel discussion with Daniel Grimm, Alpha-1 patient, about understanding clinical trials.

6 Latest Clinical Trial News and What You Need to Know

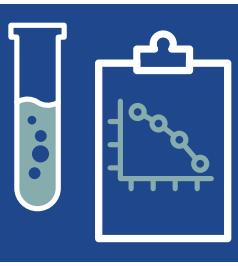
New Clinical Trials for Severe Alpha-1

The COVID-19 era brought many challenges to healthcare, and the need for rigorous, evidence-based research has never been more important. Several local, national and global COVID-19 studies were conducted at Beaumont Hospital, and have contributed to a greater understanding of COVID-19, its treatment and prevention for the future. One study looked at using purified alpha-1 antitrypsin (AAT) to treat critically ill patients with COVID-19 lung disease. The study showed promising results that will be published in early 2022.

Moving forward, there are some exciting clinical trials about to commence which are looking at new treatments for people with severe AATD (for example ZZ type). The first such study, KAMADA, is due to start recruitment in summer 2022. Eligible participants will be people who are ZZ Alpha-1. The study is a **phase III, placebo-controlled, double-blind** study to test a new inhaled form of alpha-1 antitrypsin. Beaumont Hospital is the only recruitment site in Ireland but there are many across the world. Other studies include the EARCO study, an observational study looking at the demographics and natural history of people with severe AATD across Europe, and a study called DICERNA, which will investigate treatments for people with liver disease caused by severe AATD. Both studies will start toward the end of 2022.

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 3863*.

Clinical Trials – Some Key Terms (from www.clinicaltrials.gov)



Clinical study/Clinical trial

A research study involving human volunteers (also called participants) that is intended to add to medical knowledge. There are two types of clinical studies: interventional studies (also called clinical trials) and observational studies.

Eligibility criteria

The key requirements that people who want to participate in a clinical study must meet or the characteristics they must have. Eligibility criteria consist of both inclusion criteria (which are required for a person to participate in the study) and exclusion criteria (which prevent a person from participating). Types of eligibility criteria include whether a study accepts healthy volunteers, has age or age group requirements, or is limited by sex.

Informed consent

A process used by researchers to explain to potential participants the risks and potential benefits of participating in a clinical study.

Investigator

A researcher involved in a clinical study. Related terms include site principal investigator, site sub-investigator, study chair, study director, and study principal investigator.

Observational study

A type of clinical study in which participants are identified as belonging to study groups and are assessed for biomedical or health outcomes. Participants may receive diagnostic, therapeutic, or other types of interventions, but the investigator does not assign participants to a specific interventions/treatment. A patient registry is a type of observational study.

Phase

The stage of a clinical trial studying a drug or biological product, based on definitions developed by the U.S. Food and Drug Administration (FDA). The phase is based on the study's objective, the number of participants, and other characteristics. There are five phases: Early Phase 1 (formerly listed as Phase 0), Phase 1, Phase 2, Phase 3, and Phase 4.

Placebo

An inactive substance or treatment that looks the same as, and is given in the same way as, an active drug or intervention/treatment being studied.

Principal investigator (PI)

The person who is responsible for the scientific and technical direction of the entire clinical study.

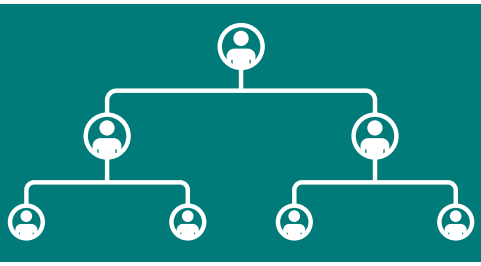
Protocol

The written description of a clinical study. It includes the study's objectives, design, and methods. It may also include relevant scientific background and statistical information.

7 Current Research in Alpha-1

Daniel Fraughen

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 mid-2022. This follows on from our two 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 the many families affected.

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.

Kate McGoldrick

Measuring The Impact of COVID-19 in Severe Alpha-1

A study by Kate McGoldrick, RCSI medical student in mid-2021 measured the impact of COVID-19 in severe AATD. As a respiratory pathogen, the SARS-CoV-2 virus was presumed to pose a heightened risk to those with severe AATD and, as such, they were advised to cocoon. 184 ZZ individuals on the National Alpha-1 Registry were contacted by phone. Information on exacerbation frequency, COVID infection status and cocooning history were collected via a survey. The overall response rate was 63.5% (n=117).

The prevalence of COVID-19 infection in the group was 12.3% (n=12) with 4.2% of cases requiring hospital admission due to COVID-19 (n=5) and no fatalities. Men who cocooned were shown to have fewer chest infections during the pandemic compared to before. People who cocooned reported a polarising effect on their alcohol consumption, and reported drinking either more or less alcohol, a known risk factor for liver disease in AATD. The process of cocooning is socially isolating and could potentially lead to an increased level of anxiety and depression due to the social isolation. Limitations of our study include the lack of COVID-19 diagnosis dates and its patient reported nature.

Róisín Fay

Newborn Screening for Alpha-1 Antitrypsin Deficiency – A Realistic Prospect?

People with AATD are at an increased risk of developing lung disease in addition to liver and skin disease. Smoking is a major risk factor for lung disease such as emphysema, with AATD smokers having a significantly worse prognosis when compared to non-smokers. Early identification of AATD through Newborn Screening (NBS) could prevent smoking-related lung disease in those with severe deficiency **and** in those with the more prevalent moderate deficiency genotypes. A student project carried out by Róisín Fay, RCSI medical student, in 2021 examined previous attempts at newborn screening programmes for AATD and explored the feasibility of adding AATD to the newborn screening panel in Ireland. The main reasons for discontinuation of AATD testing at birth in other countries were the lack of specific treatments for AATD and the negative psychological reactions observed in parents of children diagnosed.

Using NBS, AATD can be identified early so that individuals can be educated on the importance of never smoking. It is important that before AATD is considered for addition to the NBS programme the appropriate support and education systems are in place. With potential new therapies becoming available for both liver and lung disease, in addition to the known benefit of smoking prevention, NBS for AATD could soon be a very real possibility.

Irish Alpha-1 Research Published in 2021

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2. Hawkins P et al. In vitro and in vivo modulation of NADPH oxidase activity and reactive oxygen species production in human neutrophils by α1-antitrypsin. ERJ Open Res. 2021 Dec 6;7(4):00234–2021.
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Financial Report

Alpha-1 Foundation Ireland
(A Company Limited by Guarantee and not having Share Capital)
Financial Statement
Financial year ended 31 December 2021

	31/12/21	31/12/20
	€	€
TURNOVER		
Northern Area HSE	119,565	119,565
Northern Area HSE – Respreeza Grant	-	-
Donations	25,663	18,301
Other Funding	-	70
Health Research Board – HRCI/HRB Grant	-	-
	145,228	137,936
Gross profit	145,228	137,936
Gross profit percentage	100.0%	100.0%
OVERHEADS		
ADMINISTRATIVE EXPENSES		
Wages and salaries	(73,037)	(30,979)
Lab Costs	(1,152)	(18,647)
Point Of Care Health Services Ltd	-	-
Conference costs	-	-
Printing, postage and stationery	(256)	(5,393)
Computer costs & System maintenance	(3,220)	(6,087)
Travelling and entertainment	(517)	(40)
Research Costs	(1,932)	(50,000)
Accountancy fees	(6,133)	(6,117)
Bank charges	(113)	(90)
General expenses	(71)	(2)
Subscriptions	(1,495)	(3,903)
	(87,925)	(121,258)
Profit before taxation	57,303	16,678
Tax on Profit	-	-
Profit for the financial year	57,303	16,678

NOTE: Detailed financial statements are available on *www.alpha1.ie*

Acknowledgements

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- Orla Cahalane, Emma Pentony, Ella Howard, Bríd Holohan, Dr. Bill Tormey and the Beaumont Hospital Chemical Pathology Department for their continued support and assistance
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- Jean Kirwan and Linda Phoenix, members of the Beaumont Hospital Respiratory Clinic administration team
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- 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 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

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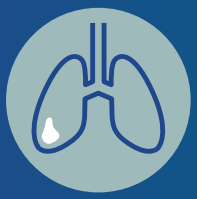
Alpha-1 Foundation Ireland Charity Code: CHY22304

@Alpha1_Ireland

Find us on Facebook

Alpha-1 is the most common genetic cause of COPD

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



Smokers with the single faulty Z Alpha-1 gene have a **10 fold** increased risk of developing a lung disease called COPD

The Irish Thoracic Society estimates approximately **440,000** people have COPD in Ireland

21,500+ people tested for Alpha-1 to date in a National Targeted Detection Programme

850+ people with Alpha-1 attend the National Centre of Expertise for Alpha-1 at Beaumont Hospital

640+ people with Alpha-1 take part in the National Alpha-1 Registry