

ASTHMA SOCIETY OF IRELAND

ANNUAL REPORT 2014

Mission:

The Asthma Society of Ireland's Mission is to save lives and improve the lives of people with asthma.

CONTENTS





I am pleased to present the Annual Report for the Asthma Society for the year ended 31 December 2014 which has been a year of significant change and progress for the Society. – Maelíosa OhOgartaigh

A Message from Maelíosa OhOgartaigh Chairperson The Asthma Society of Ireland



A Message from Maelíosa OhOgartaigh

Chairperson The Asthma Society of Ireland

2014 continued to bring governance and funding challenges to the charity sector. During the year the Charities Regulatory Authority was established. The Society welcomes the commencement of the implementation of the requirements of the Charities Act 2009 and looks forward to working with the Authority on implementing the standards expected of charities in their governance and reporting. In this regard the Board made significant progress in applying the protocols and standards required and is now in broad compliance with the requirements of the Code of Governance for Community, Voluntary and Charitable organisations (the Code). The Society remains committed to its principles of providing services and support to people with asthma and in advocating for a better environment and better services nationally. The dedication of all staff led by Sharon Cosgrove, Chief Executive Officer, in the provision of patient services, research, education and the advocacy for better services nationally is a reflection of that commitment and on your behalf I would like to state our appreciation of their efforts.

During 2014 the Board in conjunction with management and staff developed Vision 2020 a strategy to develop and enhance the provision of services and support, consistent with the Society's principles, over the next number of years. The Society has through its patient centred services provided advice and support to asthma patients through the advice line and regional clinics. The Society has also taken a leading role in developing alliances to advocate for a coal free and tobacco free society which would be of immense benefit to asthma sufferers, and in its continued advocacy for the implementation of the National Cinical Asthma Programme.

During 2014 the Board has:

- made significant progress in implementing policies and procedures consistent with the Code.
- continued to apply the Statement of Recommended Practice (SORP) for Charities in the presentation of its Financial Statements and in doing so meets the highest standard in financial reporting. The SORP provides clarity and transparency in the reporting of the Society's sources of income and in its expenditure.
- where appropriate, continued to apply the terms and conditions of the Haddington Road Agreement (HRA) on Public Sector pay. The terms of the HRA is applicable, on a voluntary basis, to charities defined as Section 39 charities. I and my Board colleagues are very grateful to the staff of the Society for

their willingness to voluntarily implement the terms of the Haddington Road Agreement and their willingness to do so is indicative of their commitment to the Society and its objectives.

During the year three new directors were appointed to the Board. I am delighted to welcome Ms Lorna Jennings, Ms Gerardine Lally, Mr Darragh McDonald and Prof. Richard Costello to the Board. I know that with their skills and experience they will be significant additions to the Board and to the activities of the Society. Dr Basil Elnazir after many years of dedicated service stepped down as Chairman of the Medical Advisory Group and as a Director and was replaced by Prof. Costello. Dr Elnazir has played a very active role in the service of the Board and the Society and, on your behalf and on behalf of the Board, I would like to sincerely thank him for his dedication and contribution to the Society.

During the year the Board met seven times and the Audit, Risk and Finance Committee and Fundraising and Communication Committee met six times and five times respectively. Our Medical Advisory Group of specialist nurses, doctors and scientists, chaired by Dr Elnazir, provided expertise, time and support to our activities throughout 2014. I would like to thank my fellow directors and the members of the Medical Advisory Group for their commitment and for freely giving of their time and expertise in the service of the Society, and its various stakeholders.

In conclusion, I have informed by fellow directors of my intention to step down as Chairman and as a Director after the Annual General Meeting. I would like to sincerely thank my fellow directors and Ms Sharon Cosgrove and her team for their support and I wish them and the Society well in their future endeavours.

Maelíosa OhOgartaigh Chairperson

1 in 5 children in Ireland have Asthma.

INTRODUCTION

2014 was another exciting year for us with increased activity in a number of areas or work. In our communication work we had excellent coverage in the media throughout the year, but especially during our World Asthma Day campaign in May and during our Back to School campaign in August and September.



Introduction from Sharon Cosgrove Chief Executive The Asthma Society of Ireland



Introduction from Sharon Cosgrove

Chief Executive The Asthma Society of Ireland In September, thanks to Lottery funding from the Department of Health, our mobile asthma clinic visited schools and town centres around the country. Partnering with Boots, we had a radio campaign and asthma support packs and pharmacists on hand in all the Boots stores during the month of May.

Our asthma nurse services expanded in 2014, with 116 in-store pharmacy clinics held. Together with the Adviceline, the nurse-led services helped more than 2,200 people manage their asthma and navigate the health services. Taking account of the changing needs of callers, in 2014 we changed the Adviceline service to a callback service and we now have a text the nurse service. So now the nurses return calls at times that best suit the busy lives of our members – whether that's a weekday, the evening or even weekends. One of our objectives as a patient organisation is to reach and help as many people with asthma as we can. In 2014 we had 40,000+ new visitors to our website and we distributed over 70,000 asthma booklets. 10 secondary schools participated in our Transitional Year E-Learning programme and for health care professionals we developed an e-zine for them and we held asthma education events on various topics, including asthma and allergies, and asthma and children. We also developed and delivered an asthma education programme to Traveller Community Health Workers in partnership with Pavee Point and supported by the Social Inclusion Unit of the HSE and Healthy Ireland.

We continued to engage and listen to the needs of people with asthma. The study we completed in 2014 which looked at Living with Asthma, as well as numerous on-line surveys gave us a great insight into the issues for people with asthma. We have used this valuable information for our policy work and in our meetings with politicians. In the coming year we will use this information and the issues people with asthma are dealing with to continue to call for improvements in asthma care, for better access to services and for the cost of asthma to be addressed.

Our success and achievements in 2014 would not have been possible without the combined efforts and hard work of the team, the Board and the Medical Advisory Group, as well as the vital and continued financial support of our donors, corporate sponsors, funders and the efforts of our fundraisers.

OUR WORK IN NUMBERS



Over **2,200** adults and children received one-to-one support through our telephone and face to face consultations



71,000 patient information booklets distributed



60,000+ reached through our digital channels



1,294 healthcare professionals registered for e-learning



21 schools received information sessions on asthma



10 schools took part in our teen e-learning programme

DIRECT SERVICES TO PEOPLE WITH ASTHMA



Some of our services have a more direct impact on people with asthma than others, whether it's our Asthma Adviceline or our clinics throughout Ireland. These direct services provide a vital route to advice and information for people who are in any way concerned about asthma, whether they're suffering from the condition themselves or enquiring on behalf of family or loved ones.

ASI Services are provided free of charge

The Asthma Adviceline

The Asthma Adviceline has been operating for over 25 years and is an important service that empowers people with asthma to manage their condition at all stages of the patient journey.

In 2014 our Adviceline went through a transformation as we introduced a call back appointment service. This made our services more flexible and client-centred. We also introduced a new quality framework under which the service operates.

The Adviceline services are delivered by our team of asthma nurse specialists, providing our clients with personalised advice and individual support. Our aim is for everyone with asthma to get their asthma under control and live life to the full, symptom free.

Clients can contact our Asthma Adviceline team on 1850 44 54 64 Monday to Friday 9am – 5pm. Our receptionist will take a few details and schedule a telephone appointment with the nurse. Appointments are available throughout the week (including Saturdays and Sundays). Clients can also contact our Adviceline team by texting 086 057 18 38 or by email to nurse@asthma.ie.

In 2014 the Asthma Adviceline helped 725 clients.

Pharmacy Clinics

997 adults and children

We continued our programme of in-store pharmacy clinics which again proved to be a very important part of our work in the community. The programme is supported by GlaxoSmithKline (GSK). To increase the uptake of our clinics to pharmacies around the country, we placed an advertisement in the Irish Pharmacy Union (IPU) Review Magazine which generated a huge response from pharmacies. A total of 115 pharmacy clinics took place in 2014 and these offered free asthma review to

Asthma Clinics

The goal of our clinics is to empower people with asthma by giving them the support, tools and information they need to take control of their asthma.

We achieve this by offering one-to-one consultations with an asthma nurse specialist to review symptoms and treatments and provide information and advice. Without the support of our asthma nurse specialists and the public's generosity, we would not be able to provide these services. All clinics are open to everyone and are completely free of charge.

Asthma clinics were held in four shopping centres around Dublin in May to mark World Asthma Day.

In September we had a mobile asthma unit which visited 10 schools and 10 town centres over a two week period. The first week the mobile unit visited the west of Ireland. The second week the unit visited the east/northeast of the country.

During our Back to School campaign in addition to visiting 10 schools with our mobile unit we also gave presentations in 11 primary schools around the country. These presentations were to teachers and SNA's. A total of 553 people had consultations with the nurse at these clinics. Many more visited our information stands at events.

Asthma Community Outreach Programme

As part of our work to address health inequalities, we designed and delivered a pilot asthma education programme to the Traveller Community in two regions in partnership with Pavee Point and with the support of the HSE. In this pilot programme we trained 29 Traveller Healthcare Workers.

Missy Collins, Primary Health Care Worker from Pavee Point, drew attention to the impact of the programme on Traveller families:

"Higher rates of asthma among Travellers have a harsh impact on our families and I feel that discrimination against Travellers makes us unlikely to seek help and support from healthcare providers. This programme set out to deliver training about asthma to Traveller Health Care Workers, who have brought the knowledge back into the community, allowing us to do strong work with families affected by asthma."

RESEARCH & EDUCATION

-



Research Activities

Living with Asthma

The qualitative 'Living with Asthma' study examined the lives of people with asthma, and was supported by Boehringer Ingelheim. Members of the Asthma Society participated in 8 focus groups nationwide and related their stories. Results were startling! They reported that the condition has 'robbed them of their lives' and that it is not taken seriously enough. Many feel frustrated and lost. Participants felt there is a "one size fits all" system of management in Ireland, and that they are not treated as individuals with specific goals and outcomes. They believe this is because asthma is so prevalent, therefore, appearing to be less important.

The need for primary care solutions is apparent, with the results of the study revealing that people with asthma feel abandoned by the system. They described their experience of disjointed services and poor follow-on care as distressing. Approximately one person a week dies as a result of asthma, yet 90 per cent of these deaths are preventable. Participants described the relentless need to be vigilant and aware of their own bodies all the time, and of the unpredictable nature of asthma, with the constant fear of things getting worse. They are limiting their activity levels, giving up hobbies and withdrawing from social and family life because of their asthma. The results of this study have helped inform our new strategic plan 'Vision 2020' and have been published in the Irish Journal of Medical Science.

Health & Wellbeing

The quantitative study, 'Health and Wellbeing of Irish Adults with Asthma', commenced during the year and was an on-line survey of Irish adults living with asthma. The study examines the relationship between asthma and health status, how those with asthma perceive their health and well-being, and how this affects their daily lives. The results of this study are expected in 2015. This study was supportedy by Novartis.

Oran O Muire Summer Scholarship

This year's scholarship award was given to Aisling Mc Getterick, a third year General BScN student, from St Angela's College, Sligo. The title of her research was 'The establishment and delivery of nurse-led asthma clinics'.

Her report showed that mismanagement of patients leads to poor control, and this had consequences for both the patient and the health care service. A number of patient-focused benefits included accessing comprehensive, individual education on asthma in a non-time bound context. Patients also benefit from the nurses' ability to tailor their engagement with them to meet their needs in relation to ongoing support. The education is also perceived to empower patients, which enhances their ability to engage with their self-management plans in a proactive manner. It was also perceived to be financially and organisationally beneficial to GP practices.

Nurses who participated reported a benefit in a variety of ways. Running a clinic was perceived to empower them as it facilitates autonomous practice, affords job satisfaction, garners respect from both fellow colleagues and patients, and allows expert knowledge/skills to be deployed in a targeted manner. The report showed the benefits of setting up nurse-led asthma clinics for all concerned.

TY Asthma e-Learning Programme

Teenagers have reported that they are less likely to manage their asthma well outside the home, because they say that their friends don't understand the condition and its management. In 2013 the Asthma Society carried out a pilot programme 'Asthma e-learning for Transition Year students' in Kinsale in Cork. This was very successful, and showed a 33% increase in understanding of the condition by those undertaking this first programme.

In 2014, 10 schools nationwide were signed up to the programme and 318 students participated. (A further 153 students are to complete the programme by the end of April 2015). There was very positive feed back from both students and teachers, and we aim to offer the programme to 20 schools in the coming year. By engaging with the students and schools, both those with asthma, and those without the condition are learning about Asthma and how to manage it themselves and by their friends or family!

Meetings

In 2014 the Asthma Society ran 2 education meetings for healthcare professionals. These were attended by General Practitioners, Practice nurses, Respiratory Nurse Specialists, Pharmacists, Respiratory Physiologists, and healthcare professionals working with patients with asthma. The first, in February, was titled 'The relevance of allergy in Asthma' and included topics - 'Common allergic disorders in children', 'Modern immunotherapy in asthma and rhinitis' and 'Skin testing in allergy assessment'. The second meeting, held in May, coincided with our World Asthma Day campaign, and the title was 'Children with asthma'. Topics at this meeting were 'Recent developments in childhood asthma care', 'Differential diagnosis of asthma', 'Asthma - don't ignore the nose!', and 'Adolescent asthma - the challenges'.

These meetings all carry CME, CPD, CEU points for healthcare professionals and offer additional and up-to-date information on asthma, allergy and COPD.

Healthcare Professional E-zine

There were 10 e-zines sent to healthcare professionals in 2014. These contained information about the Society, our healthcare professional educational meetings, how to become a member, our publications, our shop, and some up-to-date information on international news and research. These are mailed directly to 1091 healthcare professionals on our mailing list, and indirectly to members of Anail, IICMS, IPU and Practice Nurses Association via the Secretaries of their respective associations. The healthcare professional e-zine helps the Asthma Society to reach a wider audience of those caring for people with asthma, and has increased members and encouraged healthcare professionals to actively engage with the society.

MEMBERSHIP



Our membership base grew rapidly in 2014 and we reached a total number of 6,373 members at the end of the year. We value the continuous support of our members and work hard to ensure their voice is represented at a national level.

Our membership is free and offers many benefits including our biannual member newsletter Asthma News, regular e-zines, and invitations to our free Asthma Clinics, online access to our publications and asthma control test and up to 22% on devices purchased in our online shop or through our office.

Most importantly our members and supporters give us a stronger voice when we advocate on their behalf, and on behalf of all those with asthma in Ireland. Together we can continue to demand better services for people with asthma, and to realise our vision of everyone with asthma living a full life, symptom free.

Vision:

The Asthma Society of Ireland's Vision is everyone with asthma living a full life, symptom free.

1 in 5 kids can't 201 fill these



World Asthma Day (WAD), the annual global awareness day for asthma, takes place on the Tuesday after the May bank holiday. The goal of our WAD campaign is always to improve asthma care and awareness of asthma. There are many issues confronting people living with asthma in Ireland and research released ahead of World Asthma Day showed some alarming results: 13% of parents of children with asthma had been to the emergency department in the last year; 1 in 4 parents had to bring their child to an out-of-hours GP in the last year; just 17% of parents have an asthma management plan in place for their child.

Based on these results, and with 1 in 5 children affected by asthma in Ireland, the 2014 campaign theme focused on the needs of children with asthma and their parents. The goal of the campaign, entitled 'Helping Parents to Breathe Easy', was to support parents to better manage their children's asthma and help reduce the number of those depending on emergency services. We held information stands in Shopping Centres throughout Dublin City and nurse consultations in Pharmacies throughout the country. We launched a World Asthma Day Infographic with tips and information on managing asthma in children. For the month of May we extended our Asthma Adviceline hours and launched a TEXT the nurse service, so that callers could text the Adviceline asking for a call to be returned. We ran advertisements on radio and online to help raise awareness of the support available from the Asthma Society and post campaign evaluation revealed an increase to our website and Adviceline during the campaign.

We partnered with Boots Ireland to offer free 'Let's Breathe Easy' clinics and support packs in stores nationwide. The campaign activity encouraged parents to visit their local pharmacy to check if the correct inhaler technique was being used; get advice on how to get the most out of your medicines; and advice on ways to make positive changes to their asthma management. All services were offered free of charge.

Throughout the campaign we saw an increase in users of our services. Thousands of people visited the clinics and information stands, downloaded materials or watched how to videos from our website, shared the infographic on their Facebook page, dropped into their local Boots store for advice and a support pack, or called the Asthma Adviceline to get confidential support and advice on managing their child's asthma.

PATIENT EDUCATION





In 2014 we continued to provide information on asthma management though our booklets and resources. Our booklets are tailored to various audiences and are available in a hardcopy through our office or online at www.asthma.ie.

In 2014 we distributed over 71,000 hardcopies of our booklets and saw a 34% increase in the number of request received by our office team. Every 26 minutes, someone goes to A&E because of Asthma.

THE COST OF ASTHMA



Asthma estimated to cost Ireland €501 million each year

In February the then Minister for Health, Dr James Reilly, launched a new Asthma Society of Ireland report into the benefit of implementing the HSE National Clinical Programme for Asthma. *The Case for Change: Implementing the National Clinical Programme for Asthma* contains some shocking findings and argues that the cost of asthma could be vastly reduced by implementing standardised care for asthma.

The approach advocated by the Asthma Society includes an annual asthma review, standardised patient education and treatment based on international best practice guidelines. The report estimates that asthma related illnesses costs the State €501.2million per annum, €262.1million of which is the loss in productivity from asthma related absences. The then Minister for Health, James Reilly said at the launch of the report, "I welcome this report, which offers an insight into the cost of asthma in Ireland and highlights the importance of implementing the HSE's National Asthma Programme. I would like to thank the Asthma Society for their extensive work advocating on behalf of people with asthma and for the invaluable frontline services they provide; and they are to be commended for their commitment to improving asthma management nationwide."

To tackle the delay to implementation, the Asthma Society proposes in the Case for Change an initial investment of €2.5million in 2014 for the first phase of the Programme. This would result in reduced pressure on secondary health services, fewer asthma deaths, better control of asthma symptoms and a significantly better quality of life for the 470,000 people affected by asthma in Ireland. Drawing on experience abroad, the report outlined the successes achieved in both Finland and Australia following the implementation of similar models of care. The report was well received both politically and publically. Leading economist and childhood asthma sufferer David McWilliams commented, "As the largest chronic disease in this country, asthma is a huge economic burden on the Irish State. The Asthma

Society's Case for Change gives a clear picture, not only of the current costs of asthma, but also how initial investment in the implementation of the National Asthma Programme could ultimately save lives and cut the health care and productivity costs incurred because of asthma." Working towards the implementation of the HSE National Clinical Programme for

Asthma continued to be a key advocacy priority for the Society throughout 2014, and the Case for Change informed our meeting with the new Minister for Health, Leo Varadkar in October. ADVOCACY



2014 was an exciting year for the Society's Advocacy team, we continued to grow our political engagement activity and our work on the policy issues important to our members

noloy Coal Sava Li

ADVOCACY







The Society made a number of important policy submissions during 2014, including our annual pre-budget submission.

2014 submissions related to:

- standardised packaging of tobacco,
- medical card eligibility,
- universal health insurance,
- sustainable energy,
- the GP contract for under 6 year olds,
- the Department of Health strategy,
- two submissions on health technology assessments,
- charity regulation
- pre-budget submission

Our annual pre budget submission called for cheaper medication, the implementation of the National Clinical Programme for Asthma, stricter tobacco control measures and a ban on smoky coal.

We presented to the Oireachtas Committee on Health in support of the Public Health Bill (Standardised Packaging of Tobacco Products). In December we held an information seminar on the dangers of smoky coal which was attended by all the main stakeholders including the Department of the Environment, the EPA and local authorities.

COMMUNICATIONS & CAMPAIGNS



2014 was a year of growth for campaigns, with our information and support campaigns reaching greater numbers, and with events taking place in more locations throughout Ireland.

COMMUNICATIONS & CAMPAIGNS







Hayfever

This year we continued to build on our successful hayfever campaign. In 2014 we launched our handy Hayfever infographic with information and helpful tips on controlling your asthma and hayfever. We continued to offer our pollen alert service through our website, the Asthma Coach app for iPhone, and on social media, letting people with asthma know when the pollen count was high and what they could do to manage their symptoms. The pollen forecast continues to grow in popularity with an increase in visits to the forecast page of 100%, during the peak pollen months.

Back to School

Emergency hospital admissions in children with asthma increase by about 300% with the onset of the school year. As parents and children get ready for back-to-school, our awareness campaign warned of the dangers posed by asthma during these vital weeks and during the school year.

Our 2014 Back to School campaign built on previous years in terms of patients reached. Our mobile unit visited schools and towns nationwide, offering free nurse consultations, helping children parents, and teachers to manage asthma at school and home.

The message was simple: put a plan in place well in advance of your child returning to school so that everyone knows what to do if an asthma attack happens. As part of the campaign we also offered free asthma information sessions to schools throughout the country, helping teachers and schools understand the condition and support the 1 in 5 children with asthma in their class.

Digital Engagement

We continued to grow our audience on social media channels, our website and through our Asthma Coach app. Our engagement with followers on social media increased significantly in 2014. We helped a number of researchers carry out surveys to help increase our understanding of the impact of asthma on people in Ireland, and how we can support the 470,000 people living with this chronic condition. These channels give people with asthma an opportunity to share their stories, hear about the experience of others with asthma, and keep up to date with seasonal information, tips and alerts to help them manage their condition. FUNDRAISING

Fighting Sthma with

Fighting asthma with every breat

We are enormously grateful to our loyal donors, supporters and voluntary fundraisers who helped raise much needed funds for our services in 2014. Fighting asthma with every breath

Fighting asthma with wery breath

Fighting with

FUNDRAISING



Together with our fundraising team, we expanded our activity with more church gate collections, fundraising by schools, and sponsorship from people running marathons, climbing mountains, clay pigeon shooting and cycling.

For the first time ever in the Asthma Society, we had a group who did an overseas walk in Croatia, raising much needed money and having fun in the process. Our corporate sponsors helped fund lots of activity including our Adviceline, nurse led clinics and out Transitional Year Asthma E-Learning programme. With their support we also conducted two valuable pieces of research which looked at how asthma affects people's quality of life. We are especially grateful for the bequests and legacies we received in 2014 and for the kindness of the families who have been touched by asthma and who have lost loved ones to asthma.

The Asthma Society is very thankful to all our donors – for your kindness and continued support in 2014.

CORPORATE PARTNERS





FUELS IRELAND



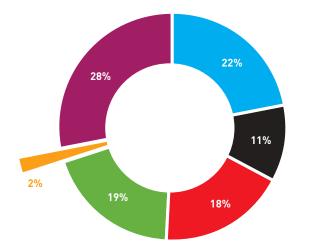




Kindly Supported By Boots Ireland

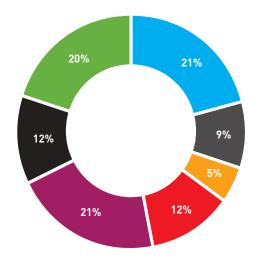
The contribution of the corporate sector to the funding particular aspects of the Asthma Society's work has become increasingly significant. We would like both to recognise this and extend our appreciation to all of our Corporate Partners who have supported our work in 2014.

GOVERNANCE AND FINANCES



ANALYSIS OF GROSS INCOME

Gross Lottery Receipts		22%
Department of Justice & Equality - Charitable Lotteries Fund Scheme		11%
Community Fundraising / Donations / Membership / Other Income		18%
Government and HSE Grants		1 9 %
Investment Income		2%
Corporate Donations		28 %
TOTAL	€1,048,453	100%



ANALYSIS OF EXPENDITURE **Direct Patient Services** 21% Information Services **9**% Advocacy and Policy 5% Research and Education 12% Communications and Campaigns 21% 12% Support Costs Finance, Administration, HR & Governance 20% TOTAL €884,810 100%

Board of Directors

Medical Advisory Group

Our Medical Advisory Group, chaired by Dr Basil Elnazir, provided expertise, time and support to our activities throughout 2014. We would like to extend our thanks to all of the specialist nurses, doctors and scientists on our Medical Advisory Group for their help in 2014.

Board of Directors

Maeliosa OhOgartaigh (Chairperson) Michael Tyndall (Company Secretary, Chair of Audit, Risk and Finance Committee) Oliver Carroll (Chair of Fundraising and Communications Committee) Prof Richard Costello (Chair of Medical Advisory Group) Deirdre Ashe Lynn Carberry Bob Gee Lorna Jennings Gerardine Lally Darragh McDonald

Director Emeritus

Anne Robinson





The Asthma Society of Ireland Fighting asthma with every breath

Charity registration number CHY6100 (Ireland). Asthma Society of Ireland. 42/43 Amiens Street, Dublin 1, Ireland. 🔰