

Foreword

2015 was a very busy year for COPD Support Ireland (COPDSI) as it continued to grow and develop as a national patient-led organisation. At the end of our second year in existence, we had some significant achievements. We were recognised in the Medical Times Awards, in the best patient organisation category, for our work on developing community-based exercise programmes with our partners. We secured some very important policy advances to enhance the rights of people living with COPD.

COPD SI's advocacy work grew steadily throughout the year, with increasing numbers of people living with COPD seeking assistance on a range of issues including, general advice and information on diagnosis and living with COPD, medical card advice and supporting applications, increased electricity bills for oxygen users and inappropriate housing.

1. Introduction

COPD Support Ireland (COPDSI) is a national organisation, led by people living with COPD, set up to raise awareness of and support those living with Chronic Obstructive Pulmonary Disease (COPD), and to advocate for action to tackle and prevent the disease. COPD SI is a young, growing and ambitious organisation established in 2013. Working with our members, we will create greater awareness of COPD in Ireland, support better services and ultimately improve the life of people living with COPD.

Our Vision Statement

That people living with COPD live the life they want to live

Our Mission Statement

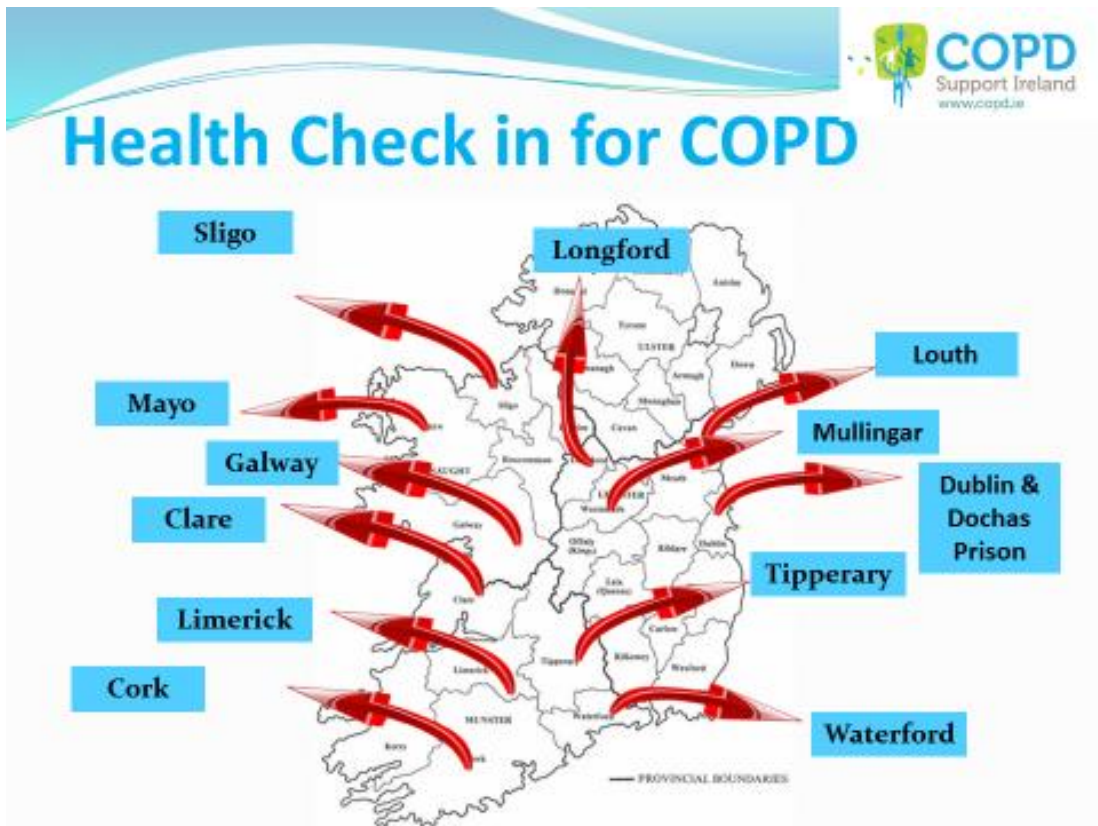
COPD Support Ireland is an advocacy and support organisation, driven by people living with COPD. Its mission is to maximise the quality of life of people living with or at risk of COPD and to support those who care for them.

The activities and actions reported in this document are all intended to reach our vision and mission statement and are part of a three-year strategic plan, 2014 to 2017.

2. Raise Awareness of COPD

Raising awareness of COPD was a key strategy pursued by COPD SI in 2015. More than 380,000 people in Ireland have COPD but 270,000 people do not know they have it. We also know that early diagnosis is critical in preventing the worst effects of the onset of COPD. COPD SI invested time in developing a communications plan which set out actions and targets to increase the level of information about COPD across Ireland. Key actions included:

- ✓ COPD SI's website was redeveloped to profile the disease and provide an update portal with key information and a range of resources for people about the disease and supports that can be accessed. A sub site was also developed to profile and spread the crucial campaign 'Save Your Breath' which was launched at World COPD Week.
- ✓ World COPD week was a huge success as we undertook a nationwide COPD health check-in tour delivering free spirometry testing to the public at eight locations across the country. This programme was carried out in partnership with a range of stakeholders, local hospitals, public health nurses and GPs to build local community-based responses to the information gap about COPD. A series of promotion events were delivered including, the launch of 'Save your Breath' campaign and the placement of articles and information in a range of media for example, medical journals, radio interviews on community based radios and advertisements on national radio.



- ✓ To coincide with World COPD Day COPD SI launched “Save Your Breath” awareness campaign which ran from Monday 16th to Friday 20th November 2015. The campaign was launched by Deputy Jerry Buttimer, Chairman of the Oireachtas Committee on Health & Children and TV3 presenter, Anna Nolan.



3. The Development of our Membership

COPD SI is committed to the development of strong local member groups to enable community-based responses to emerge in addressing self-management, lack of awareness of and lack of policy responses to COPD. This work ensures that a collective patient-led response to this disease can be developed.



At end of 2015 there were 10 active member groups in Galway, Dublin, Limerick, Cork. Mullingar, Louth, Mayo, Sligo, Tipperary, Waterford and 3 more

groups were in forming stage. COPD SI met with each group and has developed and provided templates focusing on:

- Constitution for a local group,
- Role of COPD Support Group
- Roles and functions of committee
- Agenda setting
- Financial procedures and management

[National Forum for Members:](#)



Cork Meeting April 2015

Two national meetings were held in 2015, Cork, and Dublin. At these meetings the groups inputted and planned COPD week and developed a political manifesto to enable engagement with politicians around the general election. Based on this work, the publication of the COPD Manifesto for Government set out the following demands:

1. **COPD spirometry screening:** to be made publicly available to high-risk groups—people who are over 35 years and have symptoms of persistent breathlessness, coughing with phlegm and chest infections, are current or former smokers, or who have a family history of lung conditions
2. **Pulmonary rehabilitation exercise programmes:** to be made available in all acute hospitals, due to the clear patient benefits evidenced
3. **COPD outreach programmes:** to be offered by all acute hospitals, ensuring patients are treated at home where appropriate
4. **Medical cards:** greater access needs to be provided for people with COPD in recognition of the significant health cost burden incurred
5. **National freefone helpline:** to be established for people with COPD to access information and advice from trained health professionals

4. To Effect Change

COPD SI is committed to effecting change in decision-making processes and forming partnerships with other to influence positive changes in the delivery of care and in policy responses. In 2015, COPD SI:

- ✓ Developed a partnership with Asthma Society of Ireland to explore the development an Adviceline for people living with COPD.
- ✓ Developed and sought an introduction of a monetary support for COPD patients regarding the electricity costs of oxygen therapy
- ✓ Sought the roll out of pulmonary rehabilitation, the outreach services through our participation on the COPD National Clinical Programme
- ✓ Made presentations and submissions on the need for greater access to be provided to medical cards for people with COPD in recognition of the significant health cost burden incurred.

COPD SI formed new partnerships through:

- ✓ Active membership at a national level with:
 - Irish Lung Health Alliance,
 - Medical Research Charities Group,
 - IPOSSI,
 - National Patient Forum HSE,
 - Tobacco Control Partners Group.
- ✓ Active membership at an EU level through engagement with:
 - European Federation of Allergies and Airways Diseases,
 - European COPD Coalition.

5. An Ethical, Transparent and Sustainable Organisation

COPD SI is a registered charity, CHY 20731 and during 2015 became a company limited by guarantee.

COPD SI is governed by a Board of Directors made up of 5 representatives from our member patient groups, 5 representatives from the Healthcare Professions, 3 members from the business community and 2 members from Community and Voluntary Sector.

COPD SI seeks to develop an inclusive organisational structure, procedures and sustainable funding streams to enable it to achieve its aims in an ethical and transparent manner.

In 2015 it advanced this through:

- ✓ Holding an AGM and ensuring Company requirements were met.
- ✓ 2 additional members were targeted and joined the Board.
- ✓ Policy regarding the relationship between COPD Support Ireland accepting funds from donors was developed.
- ✓ Development of good governance code
- ✓ A strategic plan was designed and developed.
- ✓ A fundraising strategy was developed and progress on its implementation achieved

There are a number of sub committees of the board:

- ✓ Health Subcommittee
- ✓ Fundraising Subcommittee
- ✓ Finance and Personnel

COPD Support Ireland Board of Directors 2015

Bernard O'Sullivan	Patient Representative
Connie Blake	Patient Representative
Betty Sutton	Patient Representative
Michael McGloin	Patient Representative
Michael Drohan	Patient Representative
Michael O'Shea	Com & Vol Representative and Chairperson
Suzanne McCormack	Com & Vol Representative
JJ Gilmartin	Healthcare Professional Representative
Máire O'Connor	Healthcare Professional Representative
Ursula Reilly	Healthcare Professional Representative
Fiona Foley	Business Professional Representative

6. Financial Report

COPD Support Ireland became a company limited by guarantee during 2014 and accounts were developed for two periods:

January to August as a registered charity

September to December 2015 as a company limited by guarantee

Our auditor for 2014 was Mark Kehoe & Co. Ltd from Cork.

COPD SUPPORT IRELAND LIMITED

PERIOD ENDED 31 DECEMBER 2014

INCOME AND EXPENDITURE ACCOUNT

2014

€

Income:

Fundraising/Event Income	112
General Donations	4,515
Corporate Donations	26,000
State Grants/Lottery	7,000
Other Income	-
Total Income	<u>37,627</u>

Less Expenses:

Salaries and Pension	13,950
Phone	101
Travel and Related Expenditure	1,065
Accountancy	1,654
Computer Maintenance	1,775
Print and Stationery	175
Insurance	586
Bank Charges	65
Training and Development	1,080
World COPD	20,035
Company Formation	495
Sundry	-
Total Expenditure	<u>40,980</u>
Excess Expenditure	- 3,353
Opening Reserves	-
Transfer Reserves from COPD Support Ireland	28,969
Closing Reserves	<u>25,616</u>

This Income and Expenditure Account has been prepared from the books and records provided by COPD Support Ireland Limited.
The period covered is September to December 2014.

MARK KEHOE & CO.
CHARTERED CERTIFIED ACCOUNTANTS
& REGISTERED AUDITORS
UNIT 2, OLDTOWN HOUSE, MAIN ROAD,
BALLINCOLLIG, CO. CORK.
TEL: (021) 4876626 FAX: (021) 4850542

COPD SUPPORT IRELAND

PERIOD ENDED 31 AUGUST 2014

INCOME AND EXPENDITURE ACCOUNT

2014

€

Income:

Fundraising/Event Income	4,149
General Donations	56
Corporate Donations	13,080
State Grants/Lottery	-
Other Income	116

Total Income 17,401

Less Expenses:

Salaries and Pension	22,150
Phone	180
Travel and Related Expenditure	1,347
Accountancy	799
Computer Maintenance	58
Print and Stationery	571
Insurance	-
Bank Charges	24
Training and Development	-
World COPD	200
Subs	150
Advert	185
Sundry	739

Total Expenditure 26,403

Excess Expenditure - 9,002

Opening Reserves 37,971

Transfer Reserves to COPD Support Ireland Limited - 28,969

Closing Reserves 0

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