



# COPD Support Ireland

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Annual Report 2020



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### Activities 2020

This year has been a challenging year for our organisation, we have strived to keep people living with COPD informed and safe during the COVID-19 global pandemic. In March 2020 all face to face group activities were suspended in line with government and public health recommendations. COPD Support Ireland had to pivot to support and deliver services using alternative methods. Fundraising was also impeded by the global pandemic with a significant reduction compared to 2019. A part-time National Co-ordinator was appointed in April 2020 to support the groups during this time and to guide the organisation through the public health crisis as well as innovating to reach the wider population of Ireland living with COPD.

Monthly virtual group representative meetings were commenced in August to re-establish two way communication between the national organisation and the 33 local support groups around Ireland. This has been a very useful project and through direct contact with the groups, the national organisation has been better able to prioritise supports that are needed at local level.

A number of projects were rolled out in 2020 including "Cocooning with COPD" an information pack that could be requested through a dedicated text line number. This pack was updated and relaunched for World COPD Day as the "Living well with COPD during COVID" information pack. Additionally "Zooming with COPD" was piloted with two groups (one Urban and one Rural) beginning in May this year where groups were restarted virtually using Zoom as a platform. The feedback from these has been positive in the main however it remains a concern that this platform does not suit all members and we must focus on engaging with these members during 2021. World COPD Day 2020 saw our first ever Virtual Wellness conference which had 6 topics, 8 speakers and attracted over 700 registrations. The event was very well received and was the highlight of the COPD Support Ireland activities for 2020.

## Objective 1



COPD Support Ireland (COPD SI) is a membership-based charity dedicated to improving the health and wellbeing of people living with COPD as well as supporting their carers and families. This is achieved through a grassroots network of 33 support groups located around Ireland providing peer to peer support, expert self-management education and COPD specific exercise programmes



## COVID-19 Response

In April 2020 the “Coocooning with COPD” information pack was launched, this consisted of an updated “COPD & Me” book which was written in collaboration with the National Clinical Programme for Respiratory, our Top 7 Tips for managing COPD, a “Staying well with COPD during Coronavirus” booklet developed with The Asthma Society of Ireland and an updated HSE COPD Communications Card. These packs could be requested by texting the word “COPD” plus their name and address to 51444. To date almost 1000 packs have been disseminated to people living with COPD and the updated “COPD & Me” books have been delivered to COPD health care professionals across Ireland.

In May 2020 the first local COPD support group virtual meeting was piloted and in July 2020 this was expanded to include two further groups with exercise provided virtually by Siel Bleu. COPD Support Ireland liaised with Age Action Ireland to utilise their COVID response “Getting Started” IT materials and their digital champion training materials to upskill volunteers recruited from the Community Call Volunteer programme to facilitate COPD Support Ireland group members accessing Zoom virtual meetings. This collaboration with Age Action Ireland has been very successful with all members wishing to meet virtually successfully mastering the Zoom platform. To date 6 groups have resumed meeting virtually with some groups amalgamating into geographical area groups to facilitate this return to weekly meetings. It is anticipated that this work will continue into 2021 with the goal to resume each of the 33 local support groups meeting on Zoom.

In June 2020 COPD SI met with the Asthma Society of Ireland to discuss increasing the numbers of COPD callers to the COPD Adviceline. COPD Support Ireland highlighted that traditional methods of communication were key to engaging the population. Additionally COPD SI promoted the adviceline in all media campaigns throughout 2020. These endeavors resulted in a significant increase in the calls to the COPD Adviceline in November. This partnership will continue into 2021 with COPD SI being invited by the HSE to assist in the growth of the COPD Adviceline to best serve the needs of people living with COPD in Ireland.

In October COPD SI once again partnered with Dr. Roisin Cahalan and Ms. Ciara Meade of the SingStrong Project to launch a virtual Singing for lung health programme. This programme has proven very popular with our members with approximately 60 people joining the weekly sessions. It is planned that this programme will continue into 2021 and will become a regular part of the COPD SI events schedule. The popularity of the SingStrong project highlighted the need for diversity in the support offerings COPD SI make. Many people who did not wish to engage with virtual platforms for their weekly exercise groups did in fact wish to participate in SingStrong. This suggests that during these unprecedented times COPD SI must adapt how they support members with activities that are engaging to them during this time rather than those that were engaging pre-Covid.

## Objective2



The current Covid-19 crisis constitutes a particular problem for patients with COPD. They are already susceptible to respiratory infections and Covid-19 could certainly be associated with exacerbations of COPD. Differentiating a Covid-19 infection from a COPD exacerbation can be difficult. COPD Support Ireland has provided multimodal communication, support and education specific to COPD and COVID-19.



## World COPD Day

This year it was decided to host a Virtual Patient Conference. Funding was sought from multiple Pharmaceutical Companies with products in the COPD market and we received a very generous sum in grant aid to produce a comprehensive educational summit for people living with COPD along with COPD Support Irelands first Media campaign to include Television and Radio Advertising. This event was hugely successful with 743 registrations to attend and a peak viewing of approximately 400 attendees. Our partnership with Age Action Ireland to support our members getting online for this event was helpful and we plan to continue this into 2021. With a modest budget for public relations, advertising creation and airing we increased the reach of this event as well as raising the profile of COPD for World COPD day. We have had some very positive feedback from this campaign which included Public Relations generated interviews and press, paid advertising on national TV and Radio, a Digital marketing campaign using social media and direct mail out to our groups as well as professional organisations and contact networks.

The success of this event is hoped to continue into 2021 with smaller virtual self-management education seminars as well as hybrid conferences to facilitate the inclusion of those who are unable to travel to an in person patient conference once public health guidelines allow such events to resume safely in our population.

## Fundraising & Grants

Fundraising was slow this year compared to others, many events were moved online and were not as well supported as in previous years. The Community Foundation with Bank of Ireland awarded COPD Support Ireland a grant of €10,000 to fund the "Cocooning with COPD" project. The Social Innovation fund was applied to for funding of our national roll out of the "Zooming with COPD" project however this was unsuccessful. HSE lottery grants were applied for on behalf of the local COPD Support Groups in September this year and we are continuing to receive notifications of awards. The RTE does Comic Relief Community Foundation grants "Demand for Digital" and "Adapt and Respond" were both applied for in order to support our groups through provision of IT Supports as well as on site technology support, upgrades to our website and digital resources. We received notification that we were successful in both applications and are looking forward to rolling out these projects in 2021.

This year COPD Support Ireland launched their Christmas card fundraiser and to date over 70 packs of cards have been sold. We have had a number of very generous donations from individuals this year as well as people participating in virtual fundraising events such as the VHI Womens Mini Marathon, Sponsored beard shaving, a 100k in 1 month run and a sponsored 1000 pogo jump fundraiser. These generous donations and creative fundraising activities have helped our organisation navigate a very challenging year.

## Objective3



COPD places a significant burden on people and the health service. Department of Health figures estimate that 500,000 people aged 40 years and over in Ireland have COPD. COPD is the commonest disease-specific cause of emergency admissions among adults and Ireland has the highest rate of hospitalisation for COPD in the OECD, double the OECD average (National Healthcare Quality Reporting System – Annual Report, 2019).

COPD Support Ireland work through local support groups and with health care professionals to assist in reducing this number through Supporting Comprehensive Self-Management Support and Education.



## Advocacy

COPD Support Ireland has represented the interests of those living with COPD in Ireland at national level through participation in the National Clinical Programme Respiratory Working Group. This year has seen the updated Model of care in COPD Outreach and Asthma as well as the updated guidelines in Pulmonary Rehabilitation as well as Virtual Pulmonary Rehabilitation being published. COPD Support Ireland has also participated in the NPHEP Vulnerable People Sub group meetings during COVID-19. During these meetings COPD SI highlighted the need for main stream media communication with the older population resulting in a number of mainstream media campaigns as well as the Ray and O'Sé afternoon exercise programme on RTE which COPD SI provided specialist chronic disease advice on. Additionally we highlighted the compromises to mental health that were being experienced by our members due to their "Cocooning" as well as the heightened anxiety levels being reported causing those living with COPD to not venture outdoors when the restrictions were being lifted. We asked for clarification on the wearing of face coverings and their becoming mandatory and sourced a supply of cloth face coverings to be disseminated to our groups in early July.

COPD Support Ireland also joined in a letter lobbying for the Pandemic Unemployment Payment to be extended to those who had been cocooning due to medical recommendations as they were not considered to be on sick leave and they were not unemployed but still could not work.

Finally COPD SI joined a group of 15 patient organisations to advocate that those living with rare and chronic diseases should be in the top priority for any COVID-19 Vaccination programme. A letter was sent to the High Level Task Force as well as the office of An Taoiseach on Tuesday 8<sup>th</sup> December. This is an issue which we will continue to pursue as a matter of great importance to our members.

## Summary

2020 has brought many unforeseen challenges to our organization but with the support of our local groups and the receipt of generous grants, donations and virtual fundraising activities, COPD SI has been able to play a key role in supporting people living with COPD as well as their families and carers during the COVID-19 global pandemic. 2021 will bring similar challenges for the COPD population especially during the early part of the year and plans to support this community are already underway.

## Objective 4



COPD Support Ireland raises awareness of COPD by representing the needs of people living with COPD and the burden of care associated with COPD at national policy level through participation in multiple national working groups such as the National Clinical Programme for Respiratory Care and most recently, the NPHEP Vulnerable People Sub-Committee.