

NEWSLETTER

FEBRUARY 2024 – ISSUE 1



CHAIRMAN'S WELCOME

I am delighted that we can bring you the first edition of what will be our regular newsletter sharing information with the members of our organisation. We hope to keep you up to date with the activities the charity has been undertaking and is planning on your behalf in 2024. We wish to share information about the various activities of individual groups around the country.

This is an important year for COPD Support Ireland as it represents 10 years since we were inaugurated as a charity. Since then, we've grown considerably through the support of our members working together with the staff and Board. However, there is still much work to be done in Ireland to achieve our vision that people living with COPD can live the life they wish to live. We invite you to celebrate our shared achievements so far and to take this milestone anniversary as an opportunity to raise awareness of COPD with the public. We are working on a number of events for 2024, starting with a national members meeting to mark World Health Day on April the 7th in Athlone, so pop it in your diaries as this will be our first in-person national meeting in many years and is a wonderful opportunity for us all to meet and celebrate the work we have achieved together over the past 10 years. The team will be sharing further details on this exciting event in the coming weeks as details are finalised.

I invite all our groups to suggest topics that you wish to see as regular items in the newsletter and, if any group would like to submit a piece for the newsletter to highlight the great work they are doing, then please do get in contact with us. In the meantime, I would like to wish you and your families a very happy and healthy 2024.

A handwritten signature in blue ink that reads 'Tim'.

Prof. Tim McDonnell,
Chairperson

TRENDING THIS ISSUE:

- 2023 Highlights
- Events
- National Office – Staff
- Events attended 2023
- New Database
- Local Support Groups
- Upcoming Events

For more information on COPD Support Ireland or to learn more about your nearest support group contact us at www.copd.ie or phone us on 086 0415128 / 083 0864118



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EVENTS – WORLD HEALTH DAY 2023

In March of last year, we hosted a very successful online webinar for **World Health Day**. Dr Ivanna McMahon, Miss Ireland 2022/2023 and GP Trainee was our charming and knowledgeable host for the event where we had a range of experts presenting on a variety of lifestyle changes we could make to improve our physical and mental health. These included TV's Chef Adrian sharing his tips on quick and healthy meals and snacks, award winning landscape gardener David Shortall who shared his tips on how to enjoy the outdoors and gardening even from a balcony; Clinical Psychologist and Operation Transformation expert Dr Eddie Murphy spoke to us about maintaining our mental wellness when living with a chronic disease; Caroline Peppard, Chronic Disease Self-Management Support Co-ordinator signposted us to a variety of local support services available in the community and through the HSE for people living with COPD and other chronic diseases. It was a fantastic event and was the pilot for our in-person World Health Day event in 2024 taking place on Sunday 7th April in the Sheraton Hotel Athlone. Keep an eye on your email inbox, social media or through your local support group for more details on this amazing event.



GET OFF THE SETTEE 4 COPD

In June of last year, we launched the **Get off the Settee for COPD** campaign where we asked members and the public to undertake some additional exercise during the month of June. Ideally to get outside in the nice weather and walk around the local park, cycle, meander or potter around the garden. Anything which increased their physical activity and improved their wellbeing. We had a great response from members participating in the challenge and several sent us photos of their activities. Well done to all who took part and keep an eye on our website or social media pages for the next exercise challenge this year.



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EVENTS – WORLD COPD DAY 2023

World COPD Day 2023 saw us becoming a host site for the inaugural International World COPD Day **Big Baton Pass**, a 24-hour live broadcast with host countries passing the virtual baton to each other and showcasing their regions COPD management and achievements, with a 24-hour virtual run undertaken by founders Russell Winwood – Social medias COPD Athlete and Ruth Barker – Respiratory Specialist Physiotherapist.

Our 2hr segment included:

- Live exercise demonstrations with volunteers from the Tallaght and Ballyfermot Support groups.
- Pre recorded presentations from physiotherapist Ciara Hanrahan on Physical Activity Behaviour Change in COPD
- Dr Marie O'Mir, Physiotherapist and CEO of the Irish Society of Chartered Physiotherapists on
- the potential role of advanced practice physiotherapists in Ireland and the work they are doing to allow the profession to deliver a broader service to people living with COPD and other conditions.
- Dr Stanley Miller, National Clinical Lead for the Respiratory National Clinical Programme on the progress of the Chronic Disease Hubs roll out as part of Sláintecare, and what these new integrated care COPD services will look like for people living with COPD.
- We spoke live with our two amazing Siel Bleu trainers on the day and also heard from Thomas McCabe, General Manager of Siel Bleu Ireland on the incredible work they are doing in delivering community-based exercise across a variety of health conditions and community groups.
- Most importantly we spoke to our volunteer members on the day and heard how the COPD Support & Exercise group has helped them to live the life they wish to live with COPD.

We also announced the results of our weeklong Step up and step out for COPD awareness challenge where we smashed the target of 380,000 steps and achieved over 1 million steps. An incredible effort from all who participated . It really was a wonderful event and a fantastic achievement from all those who took part.



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EVENTS – WORLD COPD DAY 2023

Later that day, a small group of members, staff and Board attended Houses of the Oireachtas to present to public representatives on the challenges facing people with COPD in Ireland including:

- the cost of living crisis and the energy crisis and how these impact them,
- the under diagnosis of COPD in Ireland,
- the longer than average length of hospital stay for COPD patients
- the importance of the continued support of government for the Sláintecare initiatives to shift care away from acute hospitals.

We had some great engagement with public representatives on the day and were particularly grateful to Sean Canney TD for sponsoring our talk and being a very supportive and gracious host on the day. In particular we would like to thank Michael Coakley and Catherine Craig who are group representative board members and who both spoke so well and honestly about living with COPD and the benefits of the peer support and exercise groups to people living with COPD across Ireland.



STAFFING UPDATE

We are delighted to welcome two new staff members to the COPD Support Ireland team. Ciara Gannon is our administration officer and Paula Meehan has joined Katie as support coordinator. We are delighted to have them on board as 48 groups and the back-office work of administering public funds from the HSE have meant that the workload has become more complex and therefore more time consuming.

We truly appreciate the generosity of our local groups who fundraised and donated to the national organisation in 2023, we could not continue to function without it as while there are some administrative costs included in the HSE funding, there are no salary costs included which like other charity organisations, makes recruiting and retaining good staff a challenge. Thank you all so much for your continued support, together we are significantly growing the depth and reach of the organisation to more and more people living with COPD in Ireland.

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EVENTS ATTENDED IN 2023

During 2023, COPD Support Ireland Staff attended a number of conferences to promote the organisations services. These included :

- Healthy Ireland conference in Croke Park in March,
- Irish General Practice Nurses conference in Portlaoise
- St Vincent's Hospital Health Fair in May,
- HSE Physical Activity Pathway Symposium in September
- Irish Thoracic Society Scientific meeting in Limerick in November



At two of these events we presented a scientific poster outlining the benefits of the COPD Peer Support & Exercise Groups based on analysis of the 12 weekly testing undertaken by our local group members at exercise classes. It was very well received and invaluable in both securing continued funding for our groups from the HSE in 2024 and growing health care professional referrals.

The General Manager presented at several national conferences during the year in her capacity as a patient advocate both professionally with COPD Support Ireland and personally as a carer for a child with additional needs. These included:

- Irish Platform for Patient Organisations, Science and Industry conference on Health Data Sharing in March,
- HSE Just Culture Conference in Croke Park in May
- HSE Patient Partner Conference in October.



Board member Ciara Hanrahan presented on behalf of COPD Support Ireland at the Respiratory National Clinical Programme's "Patient-Centred Integrated Respiratory Care, A holistic approach" webinar for healthcare professionals on World Lung Day in September. All these public engagements and professional events raise the profile of both COPD and the organisation through its strength in membership and its value in contributing to sustained physical activity and self-management in people living with COPD.

NEW DATABASE

As the organisation grows, we require more complex systems of work to ensure that we comply with the Charities Regulator, HSE Service Level Agreement and other legislation and funding body requirements. Thus, another milestone project was undertaken in 2023, the design and implementation of a Customer Relationship Management System (CRM) this is a database that allows us to keep all the data that we collect secure, and we can generate the reports required of us by these bodies. This project was only possible because of the generous donation of the platform licences by Salesforce's nonprofit programme and Ignyto, a platinum level salesforce implementation partner who very generously donated their services as part of their Corporate Social Responsibility programme. Together these donations of products and time are valued at over €20,000. COPD Support Ireland will save valuable administration time with this system as we were previously operating with paper-based data and multiple excel spreadsheets making it difficult to ensure that the data was up to date and complete.

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LOCAL COPD SUPPORT GROUPS

During 2023 we delivered over 1600 in person exercise classes throughout the country as well as over 120 online exercise classes. We welcomed several new trainers on board and spread our reach further into counties where we previously did not have any presence. For 2024 we will continue to build on the great work which was done last year in further strengthening and building up these groups with hopes that next year will see further new groups established.

We added 15 new support & exercise group locations with a further 3 in early 2024. These new groups were only possible due to the support and funding from the HSE through the Respiratory National Clinical Programme, the Integrated Care Programme for Chronic Diseases and the Enhanced Community Care Programme as well as local Community Health Organisations. With the help of local health & social care professionals, the respiratory national clinical programme and support of our existing group members, the following groups commenced:

Carrick On Suir	Monaghan	Tuam	Poppintree	Navan	Balbriggan	Fethercain
Newbridge	Tullamore	Athy	Enniscorthy	Cabra	Ballybough	Portlaoise

Anyone interested in joining any of these new groups should contact us on admin@copd.ie or by phone at 083 0864118 / 083 4095250.

UPCOMING EVENTS 2024

Please save the date of Sunday April 7th as this is **World Health Day 2024** and this year COPD Support Ireland will be hosting a live members event in the Sheraton Hotel in Athlone to mark not only World Health Day but also celebrate the 10th Anniversary of COPD Support Ireland.

It's shaping up to be a great day with expert speakers and demonstrations on health and wellness topics with a light lunch and an opportunity to socialise with group members from across the country afterwards. We would love for you to join us to celebrate all that has been achieved in our short 10 years in operation with an awards ceremony over lunch for the unsung heroes of COPD Support Ireland. Keep an eye on your inbox and our social media for nominations. It might even be a nice opportunity for a little trip away as we are negotiating a preferred rate at the hotel for the Sunday night. The Sheraton Athlone is a short walk away from Athlone Train station and has a nice big shopping centre attached to it for those of you partial to a little retail therapy! Further information will be available in the coming weeks with details of how to book your place at this event. Visit our website www.copd.ie

That's all from our first newsletter. We hope that you found it enjoyable and informative and for future newsletters we welcome your suggestions, comments, and input as we want it to make it a newsletter for the members. See you in May for Issue 2,

The COPD Support Ireland Team