

Review of Activities during the 12 months to 31 December 2020

This year, 2020, has been a very painful period for everyone in the country as we all struggled to cope with the consequences of the covid-19 pandemic. From March to the end of the year our activities were limited to what could be achieved by on-line and video contacts. Despite that, we did have some success in pursuing the objectives of HHT Ireland.

Raising Awareness:

Leaflet

We published our explanatory leaflet “Coping with Nosebleeds” which captured the guidelines generated by the workshop held in 2019 on this subject. This leaflet is available to all on our website as well as in printed format.

School Guide

We also published a revision of our School Guide to include Covid-19 recommendations. This revised school guide is also available on our website.

Newspaper Articles

In February, with the help of Rare Diseases Ireland, articles on HHT were printed in 5 newspapers, national and local and 8 interviews were given on radio and television.

Other

Significant effort was expended to increase activity on social media, making the name HHT Ireland more visible and guiding people with HHT to the website for information and support.

Supporting Patients and Families

Annual Forum

The annual forum, planned for May, had to be postponed and eventually abandoned due to the effects of the covid-19 pandemic. Adapting to the circumstances, Zoom meetings were held weekly (April-September) and then changed to a monthly event from Sept onwards. This allowed contact to be maintained with families and patients and to discuss problems that arose in the very changed circumstances,

Website

HHT Ireland maintains its website (HHTireland.org) which provides information and links concerning HHT. A redesign and updating of the website was carried out with the assistance of a communications consultant. Contact can be made by e-mail, Facebook or Twitter or on our dedicated phonenumber 083-4222302.

Fundraising

Annual Moveathon

Fundraising had heretofore been mostly dependent on sponsorships for participants in 2 main events – VHI Womens' Mini Marathon and Tour de Burren cycle - both of which were cancelled this year due to the pandemic. People were fantastic, however, and responded to our call to action! Our first ever virtual event – Annual Moveathon - was arranged, whereby people carried out their own walk, run or cycle within the confines of their allowed travel distances and arranged sponsors for their activity. A series of Moveathon tips were posted on our social media platforms, increasing its awareness. Participants were invited to share their photos/videos of their training sessions in advance of the Big Day. HHT Ireland later produced a ThankYou video, consisting of many short clips received. The event was deemed a great success and proceeds exceeded expectation!

Other Actions

International guidelines

HHT Ireland was delighted to be asked by CureHHT to review the draft version of the new 2nd International Guidelines, from the Patient Organisation perspective. This we did and the new International Guidelines were later published in September. HHT Ireland was very happy to disseminate these guidelines via our website & social media platforms.

Emergency Guidelines

HHT Ireland undertook the translation from the French to English of the Orphanet Emergency Guidelines for the treatment of patients with HHT. The objective was to ensure these guidelines were available in English on the Orphanet website to all relevant clinicians. We hope with the help of Orphanet Ireland, these guidelines will be published soon. Orphanet is the European website providing information on orphan drugs and rare diseases to healthcare professionals.

HHT Europe

HHT Ireland has continued to maintain active links with HHT Europe and through it with many other HHT patient organisations throughout Europe. In this way we ensure that we have up-to-date information on HHT and informed on best practice for raising awareness and supporting patients.

Rare Diseases Ireland

Also, for the same reasons, close contact has been maintained with Rare Diseases Ireland.