

Loss of smell after COVID-19: a view from the patient forums

BY CHRISSE KELLY

Patient advocate, **Chrissi Kelly**, founder of AbScent, talks about how the pandemic has changed the way we think about smell loss.

The high prevalence of chemosensory impairment as a result of the SARS-CoV-2 virus has shone a much-needed spotlight on the problem of patients experiencing post-infectious smell and taste changes. For many years a niche field that received little attention, both in the public arena and in research, olfactory dysfunction in coronavirus patients is now known to range from 64.4% to 85.9% in milder forms of the disease. This brought the matter directly to the attention of the media as patients have struggled to adjust to life without smell. As a patient with post-infectious olfactory dysfunction in 2012, and another loss of smell from COVID-19 in April 2020, I have welcomed a sea change in the way patients are seen and heard. I have been working with patients since 2015 in a closed Facebook group, and founded the charity AbScent in May 2019. In my role as patient advocate, the emphasis has been on raising awareness of olfactory loss. Awareness is with us now. The next challenge is proper support of the growing ranks of those whose sense of smell has been affected by COVID-19. Patient advocacy in this area has adapted and is providing a new kind of interaction between patients, researchers, and clinicians.

The first indication that smell loss might be a part of the coming pandemic came

“We require researchers who access our community to feed back their results, in ways that are accessible to the layperson, so that patients feel they are heard and valued”

to me on Twitter in February 2020 from Iran, followed a week later by a front-line ENT surgeon in Italy who had suddenly lost his sense of smell, without other symptoms, and was seeking advice on smell training. By March, the Global Consortium for Chemosensory Research (GCCR) was formed, where I served on the forming committee as patient advocate. At the same time that the GCCR's research was gearing up to learn more about the prevalence of COVID-19 chemosensory changes, the ranks of the original AbScent Facebook group were swelling.

On March 24, 2020, the day of lockdown, numbers in that Facebook forum had increased to the point where all discussion

was dominated by COVID-19, and this was problematic for the many members who had joined the discussion to discuss smell loss via other non-viral pathways. The dramatic rise in membership caught the attention of Professor Claire Hopkins, President of the British Rhinological Society (BRS), and Consultant, Mr Simon Gane, AbScent trustee, culminating in a letter to Rhinology on the subject [1]. As the numbers continued to grow it became necessary to add a further Facebook group to discuss parosmia and phantosmia. Today our online community, across all platforms, numbers over 65,000.

The research potential of the patient groups was soon obvious. With expanding numbers of members who represented a reservoir of real-time experience, AbScent quickly established ways of interacting with the group that would benefit members and researchers alike. We reinforce the message about the importance of members participating in research but, equally, we require researchers who access our community to feed back their results, in ways that are accessible to the layperson, so that patients feel they are heard and valued. Too often, patients are seen by researchers as merely data points. AbScent's model of patient advocacy is a virtuous circle where patients can share their stories, providing both qualitative and quantitative data, generate new research themes [2-4] and learn about the latest research. Our research with the University of Reading on parosmia is an example of original research that commenced in the pre-pandemic Facebook group [5].

The people who join our COVID-19 groups are anxious, anguished, and discouraged by lack of interest from their GPs. Their expectation is that because smell loss has originated in the nose, the support needs to come from the ENT community. Sadly, there are few medical interventions that can be offered, although interest in new therapeutics has equally increased during the last year. In our own research, and in



Growth of the COVID-19 Facebook group, March-December 2020.

