

# abScent

## Press Release

Date: 12<sup>th</sup> August 2019

### **Largest ever ‘crowd-sourced’ research project launched to support people with smell loss**

AbScent, a UK charity that supports people with smell loss, is launching the biggest ever research project of its kind into the condition.

Smell loss is a complex condition that can affect the brain’s olfactory nerve and the tissues of the upper respiratory tract. It can feel like an invisible disability and research to support those affected remains limited. Sufferers can feel anxious about the dangers of being unable to smell gas or smoke, and isolated due to a loss of intimacy with close family members and diminished social ties. Smell loss also affects a person’s ability to experience flavour, which can alter their relationship with food and lead to weight cycling.

It’s estimated that up to 5% of the UK population (over 3 million people) could be suffering from:

- anosmia - a complete lack of smell
- parosmia - a distortion of smells
- phantosmia - phantom smells
- hyposmia - reduced smell

The Sense of Smell Project is a unique collaboration between patients with smell disorders and scientists. It requires people to submit their experiences via the AbScent website ([www.absecent.org](http://www.absecent.org)). The data will be analysed by two world leaders in the area of smell disorders. By bringing people’s experiences together, and identifying clusters, it is hoped that the Sense of Smell Project will lead the way to the development of healing strategies to support patients.

Chrissi Kelly, Founder of AbScent lost her sense of smell in 2012 after a sinus infection. She says; *“Smell loss changed my life, my personality and my view of the world. It is a unique bereavement, impossible to put into words. I felt untethered from my daily experience.*

*“By the time the patient gets to the doctor, the problem has often spread beyond the nose, altering the quality of the person’s life and relationships. We don’t just need doctors; we need strategies for self-help and self-care. By launching the Sense of Smell Project I hope we can unearth much more information about smell loss, and people’s experiences, so more can be done to support patients.”*

Smell loss can affect people of all ages and for many different reasons, such as after an upper respiratory illness, a head injury or sinus disease. Rebecca Taylor, 31, from London, lost her sense of smell just six months ago, after she was hit by a speeding cyclist and suffered a head injury.

Rebecca says; *“There were some quite dark days after that just dealing with the huge sense of loss, which has been quite akin to a grieving process for me. I can tell a lot of people don’t understand the impact and I get a lot of these flippant, offhand comments like; ‘Well at least you won’t be able to smell the bad smells now’, and that’s even from people in the medical profession, including ENT doctors, which is never helpful.”*

Denise Stanton, 39, from Archway, London lost her sense of smell after a severe sinus infection and it has had a huge impact on her life. She says: *“I have a little girl and one day we were at home and one of the gas hob rings had blown out and the whole place was filled with gas and I didn’t know. My husband came home and said ‘Denise, it absolutely stinks in here, get out.’ He went around opening all the windows and I said ‘oh my god I can’t smell it’, and that really upset me.”*

Smell training has been shown to amplify recovery where there is damage to the olfactory nerve, by stimulating this nerve and encouraging it to regenerate. It uses essential oils of rose, lemon, clove and eucalyptus which are smelled twice a day for a minimum of four months. The Sense of Smell Project is being launched alongside a Smell Training app, which is the first of its kind, and will help users to track and monitor their progress.

**ENDS**

**For interviews and enquiries please contact:**

Caroline Sharp

Sharp Content Communications

[caroline@sharp-content.co.uk](mailto:caroline@sharp-content.co.uk) / 07979 756440

LOGOS AND PHOTOS CAN BE DOWNLOADED AT:

[https://abscent.org/download\\_file/255/0](https://abscent.org/download_file/255/0)

**Notes to editors:**

- **AbScent** is a UK registered charity (No. 1183468) started in 2018 to help people who are experiencing the distressing effects of smell loss.
- The Sense of Smell Project will be overseen by an international expert on smell disorders, [Prof. Thomas Hummel](#) of the University of Dresden in Germany and data analyst in olfactory studies [Robert Pellegrino](#), of the University of Tennessee.
- For more information on the latest available research into smell loss visit: <https://abscent.org/learn-us/latest-research>.

- AbScent's vision is a world where smell loss is recognised by the general population as a challenging condition, where patients are fully supported by the medical community and their care circles, and where healing strategies are explored, funded and made available to the world-wide population.
- The effects of smell loss can be complex and therefore support is necessary from several areas to suit the biopsychosocial needs of the community.
- [Smell training](#) is a supportive technique for people who have suffered smell loss and has been demonstrated in over a dozen scientific studies to be of benefit for people who have lost their sense of smell after a virus or injury.
- [Smell training](#) is not a cure, but a way of amplifying natural recovery. Every time it is done it stimulates the olfactory nerves and this encourages the nerve to regenerate. . It can be likened to physiotherapy for the nose.
- AbScent consists of Founder Chrissi Kelly, Trustees Miriam Block and ENT Simon Gane of the Royal National Throat, Nose and Ear Hospital in London, and an advisory board detailed on the website.

[www.abscent.org](http://www.abscent.org)