Mrs Ainslie Course

Glasgow

The Rt Hon Kit Malthouse MP
Minister of State (Minister for Crime and Policing)
2 Marsham Street
London SW1P 4DF

The Rt Hon Sajid Javid MP
Secretary of State for Health and Social Care
39 Victoria Street
London SW1H 0EU

22nd February 2022

Dear Mr. Malthouse and Mr Javid,

My name is Ainslie Course and I write to you on behalf of a community who experience a rare and debilitating deep brain neurological condition which at present is incurable. This condition is called Cluster Headache. I have survived this condition, which is also sadly known as "suicide headaches" for close to 37 years and I am very proud to sit on the Board of Directors for a charitable organisation called Clusterbusters whose main focus is to help improve the lives of those living with this condition.

Cluster headache is officially recognised by the medical profession as being the most severe pain a human can endure. For those living with Cluster Headache, the brutality and severity of the pain brings many challenges. It wreaks havoc on relationships, family life, employment and friendships. Our condition carries a suicide rate of twenty times the National average.

An individual Cluster Headache attack can last between 45 minutes and 3 hours and we endure between 8 and 10 attacks daily. These attacks can induce self harming with many people smashing their head on the nearest hard surface, trying to gouge out their eyeball on the offending side, and many have resorted to putting a pistol to their head.

Sadly, there are very few medications which offer any relief whatsoever, and those that do are short lasting at best but many, many people living with Cluster Headache have been successful in treating our condition with sub-hallucinogenic doses of psilocybin. Not only is this a way to treat the physical symptoms of our condition, but this medicine can also treat the associated mental ill health, that is the depression, anxiety and post traumatic stress related to knowing the excruciating pain will inevitably return. The medicine is so effective and the pain so incredibly debilitating that any risk pales in comparison. Psilocybin is helping hundreds of thousands of people to live a predominantly pain free life with encouragingly long periods of remission. This medicine has saved my life and the lives of many others.

I recently learnt that our Prime Minister Boris Johnson, in a meeting on 26th May 2021, confirmed to Mr. Crispin Blunt MP that he had approved the rescheduling of psilocybin and other psychedelic substances to facilitate research which could ultimately lead to sufferers of Cluster Headache like myself gaining legal access to the only

medicine that works for us. However, it has now been 10 months since the PM's approval and the Home Office are yet to action the Advisory Council on the Misuse of Drugs to conduct the urgent review required for this legislative change. At this point, when it is clear that the change is supported by the public and the PM, psilocybin's continuing Schedule 1 status feels like an insult to all those who must continue to break the law to access this life saving medicine.

In the US neurologists and neuroscientists are conducting research and clinical trials into this treatment with incredibly exciting results which corroborate our experiences of using the medicine but no trials into psilocybin for Cluster Headaches are currently taking place in the UK. This can be attributed directly to the Schedule 1 status of psilocybin under the Misuse of Drugs Regulations 2001. This piece of legislation indicates that psilocybin is a substance with no medicinal or therapeutic benefit. Our worldwide Cluster Headache community is proof that this non harmful and non addictive substance is the most successful and promising medicine in the treatment and management of Cluster Headache in more than 5 decades. We strongly feel that in light of the evidence the Schedule 1 designation of psilocybin should be adjusted accordingly in order to facilitate research into this life saving medicine in the UK.

On behalf of the Cluster Headache community I implore the Home Office for the urgent rescheduling of psilocybin for the purposes of facilitating research into its medicinal application in the treatment of Cluster Headache and other conditions. We encourage you to respond to the needs of our Cluster Headache community, providing us with hope that a future in which we can access our medicine legally is just around the corner. We are relying on you to help save the lives of so many people living with this incredibly debilitating condition, please act swiftly.

Yours sincerely,

Mrs. Ainslie Course Vice President

Clusterbusters Inc.

Also signed below by 161 UK Cluster Headache sufferers:

Alicia Khan Matt Willis Laura Jane Rowland
Andrew Tucker Clare Tucker Nicola Burnett
Paul Helmn James Lush

Paul Helmn Elizabeth Helmn James Lush James Knight Tracy Smith Dr. Jamie Bhagwan Darrell Elv Ellen Hughes Derek Thorburn Jess Thomas **Adam Thorne** Annette McGaffney Artur Reis Da Silva Byron Rodrigues Cecilia Pires Vivian Prado Alanis Prado Agatha Prato Julia Pollard **Rob Collins** Alex Lowe Colin Healy Dean McMahon Irene Day Reginald Day Graham Moore Mandy Moore Ellie Moore Scott Davidson Francesca Course Gary Davidson Irene McLaughlin Tom Nash

Tim Stolworthy Emma Barlow Femme Molyneux
Julie Sloan-Fortune Connor James Scully Andy McDowell
James Barker Craig Allday Steven Anderson
Debbie Waight Victoria Montague Skye Montague-Mason

Sharon Muir Trisha Owen Jason Owen Nathan Smith Linda Duddy **George Francis** Simon Francis **Craig Corbett** Chris Brook Jo Hardin **Cathal Mooney Edward Watts** Jayne Pomery Simon Jennings Dave Maulin David Dzierozynski Jamie Lee Carter Jane Arm Katie 'Hughes Megan Hughes **Bob Brown** Ally McFarlane Kate Van Den Akker Lisa Munro

Michelle King Sean Shelby-Wells Pauline McClarence

Mickey Knight-Harris Kirsten Thacker Breda Quinn
Stephanie McMahon Jayne Harding Jo Palmer
Debra Leigh Preston Nick Preston Charlie Preston
Linda Fraser Kevin Allen Emma Jones

Mandy Collins Tom Goddard Rosemary McQuillan
Duncan Patrick Paul Woodland Gerald Adamson-Eadie

Peter Horden Rhiannon Kearns Eric Renshaw Karen Hudson Jack Trainer Angela Williams Janet Fletcher Clare Carlaw Shannyn Leigh Damien Welch Katie Welch Craig Hepburn Ray Ward Aimee Grav James Gordon Linda Fraser Claire Brown Matthew Brown Ann Adamson-Eadie Andrew Macdonald Rhea Fraser Diane Devlin-Mclean McKenzie Faye Lister Mike Mayers

Kerr Fulton Kennedy Rae Sonny Ashworth Natasha Johnson Wayne Bovalentine **Anthony Farrell** Caitlin Strachan Chloe Bailey Brian Munro Liz Dawson Dave Smith Maurice Jackson Corina Breukel Chris Plastow Kate Bidder Jimmy Morissey Claire Davies Kirsten Lister Adam Wright Alison Dingwall Harvey Amanda Nathan Harley Lewis Claire Bromley Daniel Aitken Frankie Mellor Jordan Sloanes Joe Richardson Tom Wright **Clifford Smith** George Allowit

Tim Stolworthy Elliot McGaffney Charlotte McGaffney
Dean McMahon Chris Buggins Mei-Ling Buggins
Paul Aldis Maria Aldis Ellie Aldis

Brad Rodger

Copies to:

Conagh Aldis

Jeremy Hunt MP

Committee Chair, Health and Social Care Committee

Crispin Blunt MP

Chair, All-Party Parliamentary Group for Drug Policy Reform

Jeff Smith MP

Chair, All-Party Parliamentary Group for Mental Health

Dan Zeichner MP

Chair, All-Party Parliamentary Group for Life Sciences

Stuart Campbell-McDonald MP for my constituency Cumbernauld, Kilsyth and Kirkintilloch East

Jamie Hepburn MSP for my constituency Cumbernauld and Kilsyth Minister for Higher Education and Further Education, Youth Employment and Training