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Long COVID Community Sets International Awareness Date for 15th March

On 15th March 2023, those who have been impacted by Long COVID will come together for the very first <u>International Long COVID Awareness Day</u>. This annual Long COVID observance hopes to raise awareness and spread accurate information about the condition's impacts.

In January 2023, first wave Long COVID patient Angela Laffin started a grassroots movement from her living room in the U.S., sending out polls to the patient community on social media platforms to establish an awareness day to unite with support groups and Long COVID organizations internationally. "It was really no surprise that the month of March was picked for Long COVID Awareness; many of those still suffering were infected in March 2020," expressed campaign organizer Laffin. "My hope is that this awareness campaign will make the impacts of Long COVID more visible to those outside our community, plus serve as a resource connection hub for both those suffering from Long COVID and also those who may not yet know that they are suffering from this disease."

The March 15th campaign will focus on overcoming the myriad of challenges facing the Long COVID community. Our community goals include connecting to peer support channels, sharing resources, promoting Long COVID education programs, advocating for clean air and prevention, as well as securing urgent funding needed for research and reliable government data.

Long COVID, also known as Post Covid-19 syndrome, is a disabling illness with a growing list of over <u>200 possible symptoms</u>, affecting more than <u>65 million</u> people worldwide. Sufferers of Long Covid are often significantly disabled by the condition and have a drastically reduced quality of life and are unable to do many everyday tasks that are taken for granted by able-bodied individuals.

According to the latest report from the Office for National Statistics, "Long COVID symptoms adversely affected the day-to-day activities of 1.5 million people (77% of those with self-reported long COVID), with 380,000 (19%) reporting that their ability to undertake their day-to-day activities had been 'limited a lot'".¹ To date, people have lost jobs, savings, and relationships due to the complex chronic conditions Long COVID creates.

¹ Office for National Statistics, 2 February 2023

https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bullet ins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/2february2023

Jo Dainow from <u>Long Covid Support</u>, one of the main Long Covid charities in the UK, says "we are facing challenges in government acknowledgement and legislation, poor progress in expediting research and battle fatigue from the general population - but Long Covid has not gone away. Millions are suffering, millions need support and treatment."

There is no proven effective treatment for Long COVID. To make matters worse, many people living with Long COVID have been <u>gaslighted</u> by doctors and even loved ones. The March 15th campaign is critical to better inform the public about how debilitating Long COVID can be for individuals and the economy.

"The Financial Times published repeated warnings that Long Covid could create an economic crisis for the UK, yet Parliament has failed to respond effectively to this emergency. We need a plan of action," says filmmaker Joshua Pribanic, a Long COVID patient and founder of <u>LCAP</u> (Long Covid Action Project). "On 15th March we act in solidarity calling for an end to the Long COVID crisis through cross party support to find a cure."

In the UK, the Long Covid SOS, a charity focused Advocacy Group, has stated, "Let's combine all of our voices as one loud call out and support each other to make the loudest noise possible about our illness, and let's get something done. Stronger together."²

Social media plays a major role in connecting those within the Long COVID community. On March 15th, Long COVID support groups and those suffering from the illness around the world will unite to host special online events. These will include live interactive Twitter Spaces for everyone to join and learn about Long COVID. Across popular social media platforms, Long Haulers will be posting black and white images of things they can no longer do because of Long COVID, using the hashtags #LongCovidAwarenessDay and #LongCovid.

As part of the Long COVID Awareness Day events, Key Workers Petition UK, a new advocacy and campaign group for Key Workers in the UK with Long Covid, will walk from Old Palace Yard at 2:15 pm on the 15th of March to 10 Downing Street to hand deliver their Keyworker Compensation Scheme petition. "We are three key workers with Long Covid. We have started this petition on behalf of all key workers to demand the UK government provide key workers who contracted Long Covid serving our country during the pandemic with a full compensation and pension scheme. Long Covid has left key workers, including supermarket workers, carers, nurses, doctors, teachers and many more, debilitated, with completely different lives. We need compensation for our service and we need it now."³

Additionally, in order to help the public take action on #LongCovidAwarenessDay, <u>LCAP UK</u> has <u>created an online letter</u> that when signed can be sent to the UK government. The letter states, "The Office for National Statistics has just ceased carrying out their 'gold standard' Long COVID surveys. As a large and ever-growing international community, we feel that the UK government

² Long Covid SOS on Instagram, https://www.instagram.com/p/CpPWij-q_mA/

³ Key Workers Compensation Scheme Petition,

https://www.change.org/p/create-a-compensation-pension-scheme-for-key-workers-with-long-covid

is not meeting the needs of this crisis. Therefore, we, the undersigned, demand that your political office explain what steps you are taking in response to the Long COVID crisis by 16th March 2023."

The three awareness ribbon colors were also polled for by the community to represent those impacted by the illness. Tracey Thompson, another first wave Long COVID patient, has designed the Long COVID awareness ribbon the community will use to represent them. The tricolour ribbon consists of grey, teal and black: grey represents the losses and sadness from pandemic, teal represents hope and support, and black represents the loneliness and rest that comes with Long COVID. Thompson has also created graphics on the awareness website that anyone may use: https://LongCovidAwareness.Life.

Laffin has begun to petition the United Nations to get Long COVID Awareness Day officially recognized. Besides uniting those living with Long COVID, we are confident that this campaign will motivate the medical community to take more action in finding a badly-needed cure for the illness.

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