

TSC and covid-19 booster eligibility

About Tuberous Sclerosis Complex

Tuberous Sclerosis Complex (TSC) is a rare genetic condition. Every month, around 10 babies are born with TSC in the UK. TSC causes growths to develop in different organs around the body, such as the brain, lungs, kidneys, eyes, heart and skin. These growths are sometimes referred to as benign (non-cancerous) tumours. When they grow, they cause problems, it is mainly because of their size and where they are growing in the body.

TSC affects everyone differently. However, common issues can include epilepsy, kidney problems, learning difficulties and autism. In some cases, people living with TSC can be immunosuppressed as a result of certain medications.

About the Tuberous Sclerosis Association

The Tuberous Sclerosis Association (TSA) was founded in 1977, and is the only UK charity focused on improving the lives of people affected by TSC. We do this by providing support and information to the TSC community, funding important research into TSC, and campaigning on behalf of the TSC community.

Covid-19 booster eligibility

The Joint Committee on Vaccination and Immunisation (JCVI) recommends that all adults who received their first vaccine dose in phases 1-9 of the covid-19 vaccination programme should be offered a booster jab.

The TSA understands that this includes people who are affected by TSC if they:

- Live with TSC, and were considered 'clinically extremely vulnerable' (now called 'high risk') to the impact of covid-19, and were told to shield during earlier periods of the covid-19 pandemic
- Live with lymphangioleiomyomatosis (LAM)
- Live with kidney problems that cause poor kidney function, or if they are on dialysis or have received a kidney transplant
- Live with severe learning disabilities
- Live with epilepsy
- Are prescribed sirolimus or everolimus (immunosuppressant medication)

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The TSA, c/o Nightingale House, 46-48 East Street, Epsom, Surrey, KT17 1HQ
Charity number: 1039549 (England & Wales), SC042780 (Scotland)



- Live with someone who is 'immunosuppressed'. This might include, someone taking sirolimus or everolimus, with LAM or on dialysis
- Are a carer of an individual with TSC who is considered 'high risk' (previously considered 'clinically extremely vulnerable') to the impact of covid-19

The TSA recognises the importance of people receiving a booster jab of the covid-19 vaccine, and hopes that as many eligible individuals as possible in the TSC community can receive their booster jab as and when they are able to do so.

If you require any further information about TSC, please contact the TSA Support Line: 0808 801 0700 / support@tuberous-sclerosis.org.

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