Billy changed UK medical cannabis law. Patients can't wait 8 more years

Thursday 12 November, 2026

Charlotte Caldwell demands an NHS prescription cannabis reset as TRACD launches survey to expose the realities of access and use

30 October – Eight years after Billy Caldwell's fight for life changed UK cannabis law, his mother is issuing an urgent challenge to government and industry: turn a legal breakthrough into a dependable route to treatment on the NHS for vulnerable, chronically ill patients.

Ahead of the anniversary on 1 November, Charlotte Caldwell is calling for investment in rigorous clinical trials, consistent medicines, proper patient care, and a separate, evidence-led approach to adult-use cannabis.

Her message is clear: growth in private prescriptions must not be mistaken for progress towards NHS access.

"In June 2018, I watched Billy become desperately ill after his lifesaving medicine was confiscated at Heathrow. While my son lay in hospital, the medicine we had fought to bring home was being held just miles away in the vaults of the Home Office," Charlotte said.

"No mother should have to endure that.

"When the law changed that November, I believed other patients would finally have a proper route to treatment. Eight years later, we must ask a difficult question: have we built a prescription market without building an adequate pathway to NHS care?

"Patients cannot put illness on hold. They cannot wait indefinitely for research, affordable treatment or the reassurance that their medicine will be available next month.

"I fought because Billy needed his medicine. I kept fighting because I knew he was not the only one. Billy changed the law. Patients cannot wait another eight years for meaningful progress."

Industry investment

Billy's case helped bring about the November 2018 reforms allowing specialist doctors to prescribe cannabis-based products for medicinal use. Charlotte says the anniversary must now prompt scrutiny of what that change has delivered and who remains unable to benefit.

She is challenging cannabis businesses to invest in well-designed trials of specific, consistently manufactured medicines, producing evidence on safety, effectiveness, dosing and cost-effectiveness that can inform clinical practice and NHS funding decisions.

"Another product on a private prescription list is not, by itself, another step towards NHS access," Charlotte said.

"Where is the commitment to finding out which medicines work, for which patients, at what dose and with what risks? Industry must invest in that work. Selling products cannot be the end of the ambition.

"Unlicensed medicines can have a legitimate place in individual care. But vulnerable patients deserve more than a legal route they cannot afford or a treatment they cannot reliably obtain. They deserve continuity, proper monitoring and healthcare they can trust."

Controlled pilot

Charlotte is also calling for closer scrutiny of prescribing standards and a clear separation between prescription treatment and adult-use cannabis policy.

Through TRACD – Transparent, Regulated Adult-use Controlled Data – she is developing a proposal for a tightly controlled scientific adult-use pilot to gather independently evaluated evidence on public health, consumer protection and illicit-market displacement.

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“I believe we cannot put prescription cannabis care on a sound footing while avoiding an honest conversation about adult use,” she said.

“Patients need treatment based on clinical need. Adults seeking cannabis for non-medical reasons need a separate policy discussion, rather than a prescription being their only legal route.

“This is not about questioning patients’ diagnoses or taking anyone’s treatment away. It is about building appropriate pathways for different needs.

“Separation alone will not secure NHS funding. That takes credible research, clinical confidence and funding decisions. But we must stop allowing those distinct challenges to become blurred and start addressing both seriously.”

TRACD launches survey: “Tell us what is really happening.”

To bring lived experience into that debate, TRACD is launching an in-depth cannabis policy research survey for eligible adults who have consumed or purchased cannabis in the past 12 months, including prescription patients and people obtaining cannabis through the illicit market.

The survey is intended to gather anonymised responses and build a fuller picture of respondents’ experiences. By bringing together a wide range of voices, it aims to inform better research, more honest conversations and evidence-led policy.

“We need to hear what people are actually experiencing, not simply what looks reassuring in a sales pitch or sounds comfortable in a political debate,” Charlotte said.

“If you have consumed or purchased cannabis in the past year, through a prescription or the illicit market, please visit the survey and check your eligibility.

“Tell us about the benefits, the difficulties and the concerns. We need the experiences that challenge our thinking as much as those that support it.

“Silence will not improve patient care. Assumptions will not build better policy. We need people’s honest experiences to help us understand what must change.”

Take part in the TRACD Cannabis Policy Research Survey:
https://tracd.co.uk/tracd-survey-tracd-cannabis-policy-research-survey/

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About TRACD: Launched on 20 April 2026, TRACD is facilitating controlled, regulated recreational cannabis pilots across the UK, Jersey, Guernsey and the Isle of Man, generating long-term data to support evidence-based cannabis legislation.

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