# Health Secretary faces backlash over Givinostat access for DMD children



Health Secretary Neil Gray is facing significant criticism following his failure to respond to urgent pleas from families advocating for access to a new life-extending drug, Givinostat, for children with muscular dystrophy. While families are grappling with the implications of Duchenne muscular dystrophy (DMD), a debilitating condition with a life expectancy of just 26 years, Gray has drawn ire for his social media activity, which has included posts about traffic light issues and youth football.

The Sunday Mail has previously highlighted the plight of boys with DMD who are unable to access Givinostat through the NHS in Scotland, despite the manufacturer offering the drug free of charge. It is understood that fewer than 30 children are deemed suitable for this treatment, which has been shown to slow the disease’s progression.

Families have expressed devastation and anger at the lack of response from Gray. Michael Harvey, who is seeking Givinostat for his seven-year-old son, conveyed his frustration: “If only these boys with life limiting conditions were an under 13s football team and they would get two responses in three days.” His comments highlight the perceived disparity in attention given to children with chronic health conditions compared to sporting events.

In addition, public reactions on social media have reflected this discontent. One user remarked, “Thank you for taking the time to share and update us all on the traffic lights. I am wondering if you could now update us on the administration of the FREE Givinostat to the boys with Duchenne who are losing muscle every day.”

Scottish health boards have reported challenges in providing the drug through an early access programme, which is actively operational in England. NHS Greater Glasgow and Clyde cited “workload” as a factor that could delay the administration of this treatment.

Mhairi Harvey, mother of Michael, has voiced her concerns, stating, “It is a morally reprehensible and unprofessional disgrace. This life-changing, safe and free medication is being withheld from patients while a tug of war over staffing ensues.”

Lawyer Aamer Anwar has taken up the cause of the families and has written to First Minister John Swinney demanding immediate action. His correspondence addressed the distress felt by families over Gray’s lack of response to an urgent letter sent on March 21. Anwar emphasised the urgency by referencing a national newspaper headline, “Save Our Kids,” directed towards Gray.

In his letter, Anwar stated, “It did not escape the families’ notice that Mr Gray appeared to be ignoring us for some three weeks, whilst he was busy posting on social media about the lack of traffic lights in Airdrie.” He further criticised the perception of neglect in addressing the needs of vulnerable children, likening Gray’s posts to a form of “gas-lighting.”

Approximately 200 children in Scotland are currently living with DMD, a rare condition that predominantly affects boys and causes progressive muscle weakness. For families facing this severe diagnosis, securing Givinostat treatment is now a race against time. As the urgency grows, families remain steadfast in their demands for action from health officials in Scotland, hoping for a surgery solution that can bring some quality of life to their children.

Source: [Noah Wire Services](https://www.noahwire.com)

## References

* <https://www.musculardystrophyuk.org/get-involved/campaign/current-campaigns/access-to-treatments/givinostat/> - This URL supports the information about Givinostat as a treatment for Duchenne muscular dystrophy (DMD) and its availability through an Expanded Access Programme (EAP). It also highlights the challenges faced in accessing this treatment in the UK.
* <https://www.gov.uk/government/news/givinostat-conditionally-approved-to-treat-patients-with-duchenne-muscular-dystrophy-dmd> - This URL provides details on the conditional approval of Givinostat by the UK's Medicines and Healthcare products Regulatory Agency (MHRA) for treating DMD patients aged six and older. It confirms Givinostat's role in managing DMD.
* <https://www.duchenneuk.org/second-hospital-trust-starts-dosing-with-givinostat-under-early-access-programme/> - This URL supports the information about Givinostat's administration under an Early Access Programme in the UK, highlighting hospitals where dosing has begun. It also reflects the concerns and actions taken by families and advocacy groups.
* <https://nhs.uk/conditions/muscular-dystrophy/> - This URL provides general information about Duchenne muscular dystrophy, including its causes and impact on those affected. It contextualizes the urgency and importance of accessing treatments like Givinostat.
* <https://www.musculardystrophyuk.org/our-work/information/dmd/> - This URL offers further insight into Duchenne muscular dystrophy, explaining the condition and the role of Givinostat as part of ongoing research and treatment efforts. It also underlines the need for accessible treatments.