GENETIC ALLIANCE UK

An Open Letter to Prospective Parliamentary Candidates in Wales

Dear Candidate,

180,000 people in Wales live with a genetic, rare and undiagnosed condition. For too many of them, the Welsh NHS and social care system is failing to deliver equitable care. You can change that.

If elected, we urge you to champion five priorities in Parliament:

1. **Faster diagnosis**: 1 in 4 people wait more than three years for a diagnosis. Support expanded newborn screening, better awareness among healthcare professionals, and wider access to genetic testing to help end the diagnostic odyssey.
2. **Equitable access to specialist care**: Just 1 in 3 people have access to a specialist centre for their rare condition. Support commissioning reform so that everyone with a rare condition gets the specialist support they need.
3. **Better access to treatments**: Only 1 in 20 rare conditions has an approved treatment. Support greater investment in rare conditions research and ensure new therapies reach patients without unnecessary delay.
4. **Coordinated care**: Only 1 in 10 adults has a care coordinator, and just 1 in 10 adults and 4 in 10 children have a care plan. We urge you to support efforts to ensure every person with a rare condition receives coordinated care and support on their healthcare journey.
5. **Delivering a bold new rare conditions framework**: Wales must renew its commitment to delivering equitable care for everyone living with a rare condition and work collaboratively with the other UK nations to develop a successor to the UK Rare Diseases Framework.

Please support Genetic Alliance UK to re-establish the Cross-Party Group on Genetic, Rare and Undiagnosed Conditions. By supporting the CPG you will help us to bring together parliamentarians and the genetic, rare and undiagnosed community to drive meaningful change for the 1 in 17 people affected by these conditions in Wales.