x *(Insert address)*

x *(Insert date)*

Dear Deputy x *(Insert name of your local TD)*

On May 26th the Joint Committee on Health met to discuss [‘improving the lives of those affected by rare diseases and their families’](https://data.oireachtas.ie/ie/oireachtas/debateRecord/joint_committee_on_health/2021-05-26/debate/mul%40/main.pdf).

I was truly shocked to learn from this meeting that there are only 3 full time Consultant Clinical Geneticists working within the HSE at the moment. The HSE itself has said that there should be 15 Consultant Clinical Geneticists employed. Genetics is key to diagnosis, treatment, access to new drugs/therapies and family planning for people living with rare conditions. All 3 Consultants are located in Dublin; there used to be genetics clinics in Cork, Limerick and Galway, however because of limited resources there are no genetics clinics outside of Dublin any more. Waiting times for genetic services are also way too long.

This is a topic close to my heart because x *(Insert a few details explaining why/how rare conditions affect you/your family/friends/neighbours/etc If you have been able to access genetic services maybe include how long you had to wait and how genetic services - testing, consultant, counselling - helped you to manage the condition and plan for the future.)*

The government’s [Programme for Government: Our Shared Future](https://www.gov.ie/en/publication/7e05d-programme-for-government-our-shared-future/) has promised to address genetic services in its lifetime. Nothing has happened yet. I hope that you will not miss this opportunity to ensure that the government delivers on its promises to the rare disease community in Ireland. It is estimated that there are 300,000 people living with rare conditions in Ireland. We need your help today to improve the lives of those living with rare conditions and their families.

Sincerely,

*(Insert your name/signature)*