

CONVERSATION GUIDE

Usually, during a general election campaign, candidates and volunteers will be knocking on doors to talk to potential voters and raise awareness of their party campaign. This is also an opportunity for you to let your parliamentary candidates know that you would like them to support and sign up to the Pledge for Patients campaign.

Here are some ideas to help you inform your parliamentary candidates and their campaign teams about the needs of people affected by rare, genetic and undiagnosed conditions - and to get them to pledge to the campaign.

- The Genetic Alliance UK campaign is asking parliamentary candidates to sign up to three pledges. This means that if they are elected, they pledge to support patients and families affected by rare genetic and undiagnosed conditions by working to:
 - Fix the problems preventing or delaying UK patients having NHS access to rare disease medicines, treatments and care
 - Make sure the NHS is detecting people affected by rare, genetic and undiagnosed conditions as early as possible
 - Build on the UK Strategy for Rare Diseases, to ensure the UK remains a world leader in research and innovation
- In the UK, 3.5 million people will be affected by a rare disease. Which, on average, equates to over 5,000 affected individuals per constituency.
- You may wish to tell the candidate and/or their team about your interest in rare, genetic or undiagnosed conditions by answering any of the questions below:
 - Do you represent a patient organisation/are you a clinician/are you or a family member affected by a rare, genetic or undiagnosed condition?
 - How do rare, genetic and undiagnosed conditions affect your personal or work life?
 - Do you have difficulty coordinating hospital appointments for yourself or your family members?
 - Have you experienced a late diagnosis, or obstacles in gaining access to potentially life changing medicines?
- You may also wish to ask the candidates questions, eg:
 - How would you/your party's candidate support the rare disease community within the constituency?
 - What are your party's main health policies?
 - Will you sign the Pledge for Patients?

For more information on the Pledge for Patients campaign, visit www.pledgeforpatients.org.uk.

Genetic Alliance UK

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