[Insert your address]

[Insert name of your local AM]

National Assembly for Wales

Cardiff Bay  
Cardiff

CF99 1NA

[Insert date]

Dear [insert name ofAM],

**Rare Disease Day 2018**

I am/we are writing to you as my/our AM to tell you about Rare Disease Day, an international event that aims to raise awareness about rare diseases and their impact on patients’ lives.

Scleroderma and Raynaud’s UK (SRUK) is one of the charities involved in Rare Disease Day. Scleroderma is a rare autoimmune condition affecting up to 12,000 people in the UK. The condition is life limiting and can be life threatening and yet research from SRUK has revealed that people with scleroderma in the UK are waiting up to two years and visiting their GP an average of five times before receiving a diagnosis. Over a fifth (22%) made more than 10 visits to a health professional before a diagnosis was given.

Collectively, rare diseases are not rare. In the UK approximately 3.5 million people will be affected by a rare disease at some point in their life. 175,000 people will be affected in Wales alone. As my/our AM, you can show your support for patients and families affected by rare diseases by attending an event to mark Rare Disease Day 2018.

**Senedd Reception – Oriel/Neuadd, Wednesday 14 February 2018, 6-8pm**

On Wednesday 14 February 2018, Assembly Members are invited to join Rare Disease UK, the national campaign for people with rare diseases and all who support them, for the annual Senedd Rare Disease Day Reception. This event will provide an opportunity to meet and network with patients and constituents affected by rare diseases, as well as clinicians, health professionals, patient organisation representatives, researchers and industry. A Cross Party Group for Rare, Genetic and Undiagnosed Conditions is in the process of being established and further information about the progress will be available at the event.

Speakers include:

* Professor Julian Sampson, Clinical Geneticist at Cardiff and Vale UHB and Lead for the 100,000 Genomes Project in Wales;
* Sarah Bennett-Evans, a parent, and carer, of a son with Williams Syndrome;
* Dr Jayne Spink, Chair of Rare Disease UK

Please show your support by joining Rare Disease UK on Wednesday 14 February between 6-8pm to mark Rare Disease Day.

I/we look forward to your response.

Yours sincerely,

[Insert name]

**Please note:** if you require any further information about the event or the Cross Party Group on Rare, Genetic and Undiagnosed Conditions, please contact Emma Hughes on [emma@geneticalliance.org.uk](mailto:emma@geneticalliance.org.uk) or 02920748154.