[Insert name of your local MSP] MSP [Insert your address]

The Scottish Parliament

Edinburgh

EH99 1SP

[Insert date]

Dear [insert name of MSP],

**Rare Disease Day 2018**

I am/we are writing to you as my/our MSP 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 alone, 3.5 million people will be affected by a rare disease at some point in their life. In Scotland, more than 300,000 people will be affected. As my/our MSP, please show your support for patients and families affected by rare diseases by joining Rare Disease UK, the national campaign for people with rare diseases and all who support them, for the annual Scottish Parliament **Rare Disease Day Reception.** Sponsored by Bob Doris MSP the event is taking place in the **Garden Lobby on Tuesday 20 February 2018, 6-8pm.**

The 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. Speakers at the reception will provide an update on progress of the implementation of the UK Strategy for Rare Diseases and other developments affecting rare disease patients and families. They include:

* Bob Doris MSP, Convener of the Cross Party Parliamentary Group on Rare, Genetic and Undiagnosed Conditions;
* Professor S. Faisal Ahmed, Samson Gemmell Chair of Child Health, Glasgow Office for Rare Conditions
* Dr Jayne Spink, Chair of Rare Disease UK.

Please show your support by joining Rare Disease UK on Tuesday 20 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 UK Strategy for Rare Diseases, the event, or if you are interested in joining the Cross Party Parliamentary Group on Rare, Genetic and Undiagnosed Conditions, please contact Rare Disease UK on [natalie.frankish@geneticalliance.org.uk](mailto:natalie.frankish@geneticalliance.org.uk) or 07944765654.