The Honourable .XXXX
House of Commons
SWX London

Ms Julia Smith
Rare Cancers UK
Old Church Road
Cambridge

Date

On behalf of rare cancer patients in the UK

Dear (Minister)

As a constituent and rare cancers patient advocate, I am writing to urge you to ensure that the current legislation reform the government is undertaking provides rare cancer patients proper access to rare cancers Centres of Excellence and European Reference Networks, in accordance with the EU Directive .XXX:X.

Rare Cancers Europe recently released its 2014 Rare Cancers Priority Agenda. This document highlights the changes we must make to improve diagnosis and treatment of Rare Cancers in (your country), based on current evidence and on our longstanding advocacy efforts.

Specifically, Rare Cancers (your country) is recommending that new health legislation works towards removing the red tape which makes access to new treatments difficult for rare cancer patients. We urge you to include the following provisions:

- Standardise second opinions, scans & mutational analysis
- Reimburse second opinions and diagnostic tools
- Improve access to existing treatments including drug approval for small groups
- Reimbursement for "off label" use of existing and licensed drugs in Europe
- Educate doctors and pathologists to recognise rare cancers earlier (primary care/GPs)
- An Infrastructure supporting translational research/cross-border cooperation
    - Tumour banks & easy tissue transfer for research
    - Clinical trials on an international scale to maximise patient numbers
    - Harmonised European patient data registries
    - Access to patient data
    - Data protection regulation should facilitate access for health research

We urge you to work to ensure that these key provisions are considered as Parliament moves forward with efforts to reform our nation's health system.

Thank you for your attention to my request and I look forward to hearing your position on this critical issue.

Yours sincerely,

(Name)
(Postal and email address) (Telephone number)