Rare Disease UK Patient Empowerment Group

Terms of reference

1. **Constitution**

Patient Empowerment Group (PEG) is a collaborative forum which enables patient representatives with an interest in rare and genetic conditions to come together to support one another in their efforts to represent people living with rare, genetic and undiagnosed conditions. PEG gives input to the implementation of the UK Rare Diseases Framework and broader policy related to rare and genetic conditions. The Department of Health and Social Care and its arm's-length bodies consult PEG to ensure that the rare disease patient community is informed and effectively represented in the implementation of the UK Rare Diseases Framework.

2. **Governance**

Meetings will take place quarterly, with the possibility of additional meetings if a topic requires more immediate attention. In the spirit of transparency, summaries of each meeting will be published online. Genetic Alliance UK will provide secretariat support.

Each member should attend all meetings if possible and make active contributions, but it is understood that this is a voluntary group and so members will attend meetings which correspond to their interests and in which they feel their contribution is most valuable.

The group will report to individual organisational structures.

PEG will take responsibility for:

1) Ensuring the representation of all patient interests in activities under the UK Rare Diseases Framework
2) Providing their expertise and input on areas which a patient perspective is requested
3) Working in the interest of mutual benefit by acting as advocates for all people living with rare and genetic conditions to their fullest ability; having the wider rare disease community at the centre of their decision-making.
4) Working collaboratively with members of the PEG and external groups to inform implementation efforts.
5) Supporting the understanding of and action to address equality and equity of access and where there are issues of health inequality.

3. Membership

The membership aims to be a representative sample of the rare disease landscape, with representation able to give input on issues of intersectionality.

Membership should rest with a single individual from each organisation whose responsibility it is to ensure attendance. Transfers of membership must be discussed with the secretariat. However, it is the prerogative of the members to invite colleagues to meetings who may provide insight on a particular agenda.

The current membership is listed below. Activity is underway to increase representation from the youth voice.

PEG consists of patient representatives from both Rare Disease UK supporters and and Genetic Alliance UK members:
Allison Watson, Ring 20 Research and Support UK
Amanda Mortensen, Batten Disease Family Association
Angela Metcalfe, HAE UK
Bob Stevens, MPS Society
Bobby Ancil, Muscular Dystrophy UK
Caroline Davies, Neurological Alliance
Charlotte Gerada, Huntington's Disease Association
Chelsea Wong, Rare Youth Revolution
Claudia Beard, SWAN UK
Ellie Davies, Cystic Fibrosis Trust
Emma Hughes, Genetic Alliance UK
Emma Kinloch, Salivary Gland Cancer UK
Georgina Morton, ArchAngel MLD Trust
Heather Delaney, Fibrous Dysplasia Support Society UK
Helen Santini, Huntington's Disease Association
Jane Swainson, Relapsing Polychondritis Awareness and Support
Jess Hobart, The UK Mastocytosis Support Group
Jo Balfour, Cambridge Rare Disease Network
Jonathan Gibson, Metabolic Support UK
Karen Harrison, Alex – The Leukodystrophy Charity
Kate Learoyds, NSPKU
Kerry Leeson-Beevers, Alström Syndrome UK
Kirsty Hoyle, Metabolic Support UK
Kye Gbangbola, Sickle Cell Society
Lesley Booth, Cambridge Rare Disease Network
Louise Fish, Genetic Alliance UK
Louise James, SWAN UK parent representative
Marie Pritchard, SWAN UK parent representative
Maxine Tapp, PSC Support
Natalie Frankish, Genetic Alliance UK
Nick Meade (Chair), Genetic Alliance UK
Nigel Over, Independent capacity
Pat Roberts, ArchAngel MLD Trust
Patrick Toland, Northern Ireland Rare Disease Partnership

Peter Freeman, Independent capacity
Phillipa Farrant, England Rare Diseases Framework Delivery Group
Rachel Clayton, Genetic Alliance UK
Rick Thompson, Beacon for rare diseases
Roanna Maharaj, UK Thalassemia Society
Rob Burley, Muscular Dystrophy UK
Ruth Sands, Huntington's Disease Association
Sam Mountney, Neurological Alliance
Sarah Wynn, Unique
Sophie Peet, Genetic Alliance UK
Sue Farrington, Scleroderma & Raynaud's UK
Sue Millman, Ataxia UK
Toni Mathieson, Niemann-Pick UK
Tony Thornburn, Behçet's UK