

CROSS-PARTY GROUP ANNUAL RETURN

NAME OF CROSS-PARTY GROUP

Cross-Party Group on Rare Diseases

DATE GROUP ESTABLISHED (the date of establishment is the date in this parliamentary session that the Group held its initial meeting, where the office bearers were elected and not the date that the Group was accorded recognition. All Groups should hold their AGMs on, or before, the anniversary of this date.)

June 25th 2013

DATE OF MOST RECENT AGM

June 10th 2015

DATE OF PRECEDING AGM [this date is required to aid clerks in verifying that the most recent AGM has taken place within 12 months of the previous AGM]

June 17th 2014

DATE ANNUAL RETURN SUBMITTED

7th July 2015

GROUP MEETINGS AND ACTIVITIES

Please provide details of each meeting of the Group including the date of the meeting, a brief description of the main subjects discussed and the MSP and non-MSP attendance figures.

Details of any other activities, such as visits undertaken by the Group or papers/report published by the Group should also be provided.

The Cross Party Group on Rare Diseases met twice in the 2014/15 session. There were fewer meetings than intended in this session – it was decided that a meeting in the Autumn would not be necessary, given the activities of patient group members surrounding the independence referendum. As there was a Parliamentary Reception to mark Rare Disease Day on February 24th, where key speakers from the Scottish Government, academia and patient groups were invited to provide insight into recent developments with Rare Diseases in Scotland, and so no meeting of the CPG

took place in the Spring.

Meeting: Tuesday 3rd of December 2015 (5.30pm)

This meeting, chaired by Malcolm Chisholm MSP, focused on the topic of access to new medicines for Rare Diseases. Kathryn Fergusson, Head of Medicines at the Scottish Government, was invited to speak about recent changes, the Scottish Government's response to the Health and Sport Committee Inquiry into New Medicines and the New Medicines Fund. Ann Lee, from the Scottish Medicines Consortium, was also invited to provide a presentation on the impact of changes to the way medicines for rare diseases are assessed by the Scottish Medicines Consortium, including the positive developments in patient engagement activities and patient involvement in SMC decision making. There was lively discussion from the patient group members on the impact of these changes and the potential for future developments.

The second part of the meeting focused on a specific issue affecting primary immunodeficiency patients in NHS Lothian. Patient groups, clinicians, nurses and patients spoke about the lack of an Adult Immunology Service which was significantly impacting the care of patients with rare, primary immunodeficiencies (and other conditions). The Chair agreed to write to the Health Board and follow up on this issue. As a result of this, and as a result of campaigning by patient groups, steps have been taken by NHS Lothian and the Scottish Blood Transfusion Service to recruit staff for an adult immunology service.

In attendance were representatives from a number of patient groups, clinicians, nurse specialists and patients. This included representatives of the Tuberous Sclerosis Association, Turner Syndrome Support Society, PID UK, UK PIPS, Haemophilia Scotland, PNH Scotland, Funny Lumps, The Brittle Bone Society, PSP Association, AGSD UK and Genetic Alliance UK. Clinical staff from a variety of Health Boards (NHS Lothian, NHS Greater Glasgow and Clyde, NHS Tayside) were also in attendance. In total, 18 non-MSPs.

The meeting was chaired by Malcolm Chisholm, with Nanette Milne and Roderick Campbell briefly in attendance.

Attendance: 3 MSPs and 18 non-MSPs

Scottish Parliament Event – February 24th 2015

There was an excellent event in the Scottish Parliament to mark International Rare Disease Day, with Professor Tim Aitman speaking about developments in genomic sequencing and the potential for vast developments in the field of rare diseases. We also heard from speakers who gave passionate insights to life affected by rare disease and shared their stories to highlight that there are many commonalities across different rare diseases and that there must be joined up thinking about the broad spectrum of rare diseases – because collectively, rare diseases are not rare at all.

As a result of this meeting, a Spring meeting of the CPG was not required.

Meeting – June 10th 2015 (1pm)

Chaired by Bob Doris, with Malcolm Chisholm in attendance, the June meeting of the Cross Party Group on Rare Diseases focused on the issue of specialist nursing for rare diseases. Natalie Frankish (Genetic Alliance UK) provided an overview of the First Minister's announcement of £2.5million funding for specialist nursing and the proposed review in to specialist nursing by the Scottish Government. We heard from Marie McGill (Lead for the Single Gene Complex Needs Service) on the value of specialist nursing for rare and genetic conditions and from Mr Prince Obike, who spoke passionately of the need for specialist nurses to reduce accident and emergency admissions and improve the standard of care of patients and families affected by Sickle Cell Disease. There was discussion amongst those in attendance about the importance of specialist nursing in rare diseases and the need for decisions on allocation of funding to be made at a national, and not a Health Board, level. It was agreed that the CPG would write to the Chief Nursing Officer, Scottish Government and Cabinet Secretary for Health and Wellbeing explaining the need for such decisions to be made nationally.

The meeting also heard from Kathryn Fergusson (Head of Medicines, Scottish Government) who provided an update on the Scottish Government's announcement on additional funding for the New Medicines Fund and provided some information on the recent statistics, due to be presented to the Health and Sport Committee, on the number of patients accessing medicines for rare diseases. There was a discussion on the Pharmaceutical Price Regulation Scheme and it was agreed that the CPG would produce a briefing paper on this topic ahead of the next meeting.

The final part of the meeting heard from Dan Farthing (Haemophilia Scotland) who spoke about the patient and family perspective of the findings of the Penrose Inquiry in to contaminated blood.

The meeting also comprised the AGM. Malcolm Chisholm and Bob Doris were returned as Co-Conveners and Natalie Frankish as Treasurer and Secretariat.

In attendance were 16 representatives of patient groups/charities including: The Turner Syndrome Support Society, The Sickle Cell and Thalassemia Support Group, The Tuberos Sclerosis Association, Haemophilia Scotland, PNH Scotland, Neutropenia UK, The Cystic Fibrosis Trust, Cancer Research UK, EDS UK, PID UK, Behcet's Syndrome Society, Action Duchenne, Funny Lumps and Genetic Alliance UK. There were a number of patients in attendance, specialist nurses representing the Single Gene Complex Needs Service, representatives from Pfizer and the Ethical Medicines Industry Group. In total, 23 non-MSPs.

Attendance: 2 MSPs and 23 non-MSPs

Other points to note:

In July 2014, the Scottish Government published 'It's not rare to have a rare disease', the Scottish Implementation Plan for Rare Diseases. We are grateful to the Clinical

Priorities Team at the Scottish Government for their efforts to engage with the Cross Party Group on Rare Diseases to encourage patients, patient groups and other stakeholders to share their views and to feed in to the development of the Scottish Plan. We are grateful to Liz Porterfield for attending a number of meetings in the 2013/14 session to update on the progress of the Plan and gather views from the Rare Disease community. The Cross Party Group on Rare Diseases will continue to input to the work of the Scottish Government where appropriate, and monitor the progress of the Plan's implementation.

We are grateful to Aileen McLeod MSP for her membership and input to the CPG on Rare Diseases. Aileen McLeod resigned from the Cross Party Group following her appointment as Minister for Environment, Climate Change and Land Reform.

The next meeting of the CPG is due to be held on the 8th of September 2015 at 7.30pm.

MSP MEMBERS OF THE GROUP

Please provide names and party designation of all MSP members of the Group.

Bob Doris (SNP)
 Malcolm Chisholm (LAB)
 Jackie Baillie (LAB)
 Nanette Milne (Con)
 Richard Lyle (SNP)
 Ken Macintosh (LAB)

NON-MSP MEMBERS OF THE GROUP

For organisational members please provide only the name of the organisation, it is not necessary to provide the name(s) of individuals who may represent the organisation at meetings of the Group.

Individuals

Organisations

Genetic Alliance UK
 Turner Syndrome Support Society
 PNH Scotland
 Laurence Moon Bardet Beidl Syndrome Society
 Brittle Bone Society
 Carers Trust
 Cystic Fibrosis Trust

	TSA Association Fragile X Society PID UK UK PIPS Haemophilia Scotland Funny Lumps Cancer Research UK Neutropenia UK Hypopara UK
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GROUP OFFICE BEARERS

Please provide names for all office bearers. The minimum requirement is that two of the office bearers are MSPs and one of these is Convener – beyond this it is a matter for the Group to decide upon the office bearers it wishes to have. It is permissible to have more than one individual elected to each office, for example, co-conveners or multiple deputy conveners.

Convener	Malcolm Chisholm MSP (Co-convener)
Deputy Convener	Bob Doris MSP (Co-convener)
Secretary	Natalie Frankish (Genetic Alliance UK)
Treasurer	Natalie Frankish (Genetic Alliance UK)

FINANCIAL BENEFITS OR OTHER BENEFITS RECEIVED BY THE GROUP

Please provide details of any financial or material benefit(s) received from a single source in a calendar year which has a value, either singly or cumulatively, of more than £500. This includes donations, gifts, hospitality or visits and material assistance such as secretariat support.

Details of material support should include the name of the individual providing support, the value of this support over the year, an estimate of the time spent providing this support and the name of the organisation that this individual is employed by / affiliated to in providing this support.

Groups should provide details of the date on which the benefit was received, the value of the benefit and a brief description of the benefit.

If the Group is not disclosing any financial information please tick the box to confirm that the Group has considered the support received, but concluded it totalled under the threshold for disclosure (£500).

Genetic Alliance UK supplies funds to provide catering at meetings of the Cross Party Group on Rare Diseases. This breaks down as follows:

November meeting – £45

June meeting - £0 (no tea/coffee order placed)

Catering total = £45

The Secretariat for the Cross Party Group on Rare Diseases is provided by the Development Officer for Scotland employed by Genetic Alliance UK. Approximately two days per calendar month are allocated to tasks relating to the support of the Cross Party Group including research, producing materials, liaising with members, general admin and arranging meetings. The estimated value of the support over a one year period is as follows:

Salary: £4429.50 per year

Overheads/Material costs: £1,368 per year

total = £5842.5

SUBSCRIPTION CHARGED BY THE GROUP

Please provide details of the amount charged and the purpose for which the subscription is intended to be used.

N/A

CONVENER CONTACT DETAILS

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