

APPG on Endometriosis Inaugural Meeting Summary Minutes

Tuesday 15th October 2024, 11:00-11:45

Meeting Room O, Portcullis House

Attendees:

- Bell Ribeiro-Addy MP, Chair
- Sir Alec Shelbrooke MP, Deputy Chair
- Rachel Taylor MP was represented by Isobel Blackburn
- Liz Twist MP was represented by staffer
- Alistair Strathern MP
- Andrew George MP
- Olivia Bailey MP
- Josh Fenton-Glynn MP
- Cat Eccles MP
- Kirsteen Sullivan MP
- Catherine Fooks MP
- Paul Waugh MP
- Matt Turmaine MP
- David Simmons MP was represented by staffer
- Steve Yemm MP
- **Baroness Golding**
- Fatima from Baroness Golding's office
- Baroness Bennett of Manor Castle
- Baroness Healy of Primrose Hill
- Lord Bruce of Bennachie
- Jo Campion, Secretariat
- Emily Manning, Secretariat

1. Welcome

The meeting was opened by Bell Riberio-Addy MP (Chair) who introduced the All-Party Parliamentary Group (APPG) on Endometriosis and welcomed everyone in attendance.

Apologies received from Gill Furniss MP.

2. Election of Officers

The APPG duly elected the following Officers with no other nominations or objections:



All Party Parliamentary Group appg Endometriosis

- Bell Ribeiro-Addy MP as Chair. Sir Alec Shelbrooke MP proposed and Baroness Bennett seconded.
- Sir Alec Shelbrooke MP as Deputy Chair. Bell Ribeiro-Addy MP proposed and Josh Fenton-Glynn MP seconded.
- Gill Furniss MP and Rachel Taylor MP as Officers. Bell Ribeiro-Addy MP proposed and Sir Alex Shelbrooke MP seconded.

Bell Ribeiro-Addy MP read out the membership list and added new members Paul Waugh MP, Matt Turmaine MP, Catherine Fooks MP and Steve Yemm MP who were in the room.

3. Confirmation of Secretariat

Endometriosis UK was re-elected as Secretariat to the Group. Josh Fenton-Glynn MP proposed and Bell Ribeiro-Addy MP seconded.

4. Future topics for discussion

4.1. Summary of discussion held by endometriosis community in July 2024

- Parliamentary members were provided with a summary of the discussion amongst the endometriosis community earlier in the year. The Secretariat explained that this group is made up of individuals with endometriosis, healthcare professionals, academics, support groups and patient organisations.
- The issues of particular concern to stakeholders were: diagnostic delays, • research and development of new diagnostic tests, gynaecology waiting times, delays in accessing treatment, equality and diversity initiatives including disparities for specific groups in accessing diagnosis and care.
- The Secretariat described how 27 stakeholders either attended the meeting or fed back through a survey and all these views have been represented in the summary.

4.2. Suggestions from Members on topics of interest

Bell Ribeiro-Addy MP opened a discussion with all members on topics of particular interest. A wide-ranging discussion followed covering suggested action and the following areas for consideration:

- Issues raised in advance of any health reform or white papers.
- New treatments, including less invasive treatments.
- Waiting times for diagnosis and treatments, looking at both long-term and short-term solutions.
- Activity to inform health budget allocations, including health research and development, and exploration of the wider costs to the public purse resulting from long diagnosis times and delays to endometriosis care.
- Influencing and coordinating with broader women's health debates and inequality of access and care.



- Working with other APPGs to amplify voice and secure backbench debates •
- Education for young women and healthcare professionals about endometriosis.
- Workforce training and workforce planning for gynaecologists. •
- Consideration of an Early Day Motion. •
- Engaging with Scotland, Wales and Northern Ireland and sharing any good • practice.
- Health equalities data, quality of care and waiting times for marginalised groups.
- Endometriosis and international development aid, international research and travel for treatment overseas.

5. Review of the name and purpose of the Group

The name and purpose of the Group were agreed upon and confirmed by the Chair and Deputy Chair.

6. Next meeting

The date and time of the next meeting will be decided shortly by the Chair.

7. AOB – No points were raised

8. Summary of actions

- The Secretariat was asked to look into figures on how many gynaecologists there currently are and how many are needed to meet demand with the Group.
- The Secretariat was asked to look into how much endometriosis is included in international development/aid.
- The Secretariat was asked to share the Women's Health Economics Report by the NHS Confederation with the Group.
- The Secretariat was asked to draft a letter for the Officers to consider sending to the Chancellor ahead of the budget.

Reports:

- National Confidential Enquiry into Patient Outcome and Death (NCEDPOD) Report on Endometriosis, 2024, NCEPOD - Endometriosis: (2024)
- Women's Health Economics Report, NHS Confederation, 2024, Women's health economics: investing in the 51 per cent | NHS Confederation