

Minutes - APPG on Osteoporosis and Bone Health

Monday 4th December 14:15 – 15:45

Parliamentary Attendees – Lord Black of Brentwood, Wera Hobhouse MP, Baroness Jenkin, Baroness Donaghy, Baroness Chisholm, Lord Shinkwin

Apologies: Judith Cummins MP

Welcome from the Chairs

Lord z of Brentwood, Co-Chair of the APPG, welcomed attendees. The minutes of the previous meeting were confirmed by the group.

Lord Black thanked the Royal Osteoporosis Society (ROS) and all volunteers and parliamentarians who contributed to the very well-run *Better Bones* campaign. Lord Black noted the disappointment after the lack of an announcement on Fracture Liaison Services (FLS) in the Autumn Statement, but explained that the purpose of this meeting is to reflect on the campaign so far and discuss next steps.

Video- *Shedding Light on an Invisible Crisis*

A video produced for World Osteoporosis Day was shown.

Better Bones campaign update and reflections from a patient

Craig Jones (CJ), CEO, ROS, gave an update on the Better Bones campaign for universal, quality-assured Fracture Liaison Services. CJ thanked volunteers for sharing their lived experiences, which have been a key part of press coverage. CJ noted broad coalition of parliamentarians, medical experts, trade unions and charities that back the campaign.

Valerie Farr (VF), osteoporosis patient, reflected on the recent Autumn Statement. VF described the difficulties of her own condition and the importance of this campaign in aiming to improve the quality of life for people with osteoporosis. VF explained how hopes of osteoporosis patients were raised after positive receptions from parliamentarians at political party conferences and the announcement of a 'transformation fund' for FLS by the Lords of Evans of Rainow in the House of Lords on September 14th. VF expressed frustration after the omission of this funding in the Autumn Statement.

CJ expressed concerns that Government not delivering on this and several other commitments will erode trust and confidence in parliament for many people with osteoporosis.

CJ outlined the next steps for the campaign. The ROS and partners will target the Major Conditions Strategy and the spring budget. The Sunday Express newspaper has confirmed that it will continue its regular coverage of the campaign. CJ met with Andrew Stephenson, the Minister for Health and Secondary Care, and is arranging for the Minister to visit an FLS. The ROS will continue to make the case for a National Specialty Advisor for Osteoporosis. The Daily Mail newspaper will begin a campaign of coverage on osteoporosis in the new year.

Discussion

Lord Black of Brentwood asked what the most important thing parliamentarians can do to assist with the campaign.

CJ would be grateful for any set piece parliamentary moment such as Westminster Hall debates and PQs.

Baroness Jenkin asked if there has there been an explanation provided to why Lord Evans of Rainow made the announcement on FLS that was not fulfilled.

CJ explained that an official letter saying that the announcement was an error was sent to peers who had attended the debate was provided the next day. CJ pointed out that this was not the only commitment that has not been fulfilled on osteoporosis this year and highlighted several other occasions.

Lord Shinkwin thanked CJ for leadership and clarity of requests for parliamentarians. Lord Shinkwin suggested that volunteers should write to their MPs and prospective parliamentary candidates in their constituency to highlight these issues.

ACTION: ROS to work with volunteers to write to prospective parliamentary candidates

DXA (bone densitometry scanning) facilities report launch

Lucy Bramwell (LB), Head of Policy, Public Affairs and Service Influencing, ROS, and Jill Griffin (JG), Head of Clinical Engagement, ROS introduced the ROS's new report on DXA (bone densitometry scanning) facilities.

JG gave an overview of the purpose of the review and its findings. The ROS conducted a DXA facilities audit on infrastructure, workforce and quality by means of an FOI request to 160 NHS Trusts and Health Boards across the UK. 137 responded – a response rate of 86%.

The APPG held an evidence session to hear oral evidence from four expert clinicians and one person with lived experience of osteoporosis

and DXA service provision. These experts detailed the challenges facing DXA services, and the impact these are having on care.

This review found how DXA provision has deteriorated in terms of capacity, workforce and now quality – to a point which is, in some instances, of grave concern and which, may breach regulatory requirements.

LB presented on a selection of the report’s recommendations which include measures to improve the quality of DXA scanning and reporting.

Discussion

Lord Black of Brentwood asked LB and JG if they could pick one recommendation that will make the biggest difference.

LB and JG agreed that this would be ensuring the quality of reporting and scanning is fit for purpose and safe and effective for patients.

Lord Black of Brentwood asked whether there is a postcode lottery for access to a quality DXA service.

JG and LB explained that there was. The data shows how much quality of services can vary as well as the difficulty of geographical access to services in some areas.

AOB

Wera Hobhouse MP thanked the ROS for its work as secretariat to the APPG.

Zoe Paskins, Consultant and Researcher at Keele University, is involved in a trial with pharmacists looking at the primary care management of osteoporosis. Feedback from interviews with these pharmacists has been that many want to play a bigger role in primary practices but cannot as osteoporosis receives so few points on the Quality and Outcomes Framework (QOF). Zoe asked if the group would look at this in future work.

ACTION: ROS to arrange a meeting with Zoe Paskins to discuss these findings and future work in this area

LB added that this may be relevant to the APPG’s work next year on access to medicines for people with osteoporosis.

Closing remarks from Chairs

Lord Black of Brentwood thanked all attendees. The next meeting date has not been confirmed but will be by early March.

*The Royal Osteoporosis Society (ROS) aims to increase awareness and discussion of osteoporosis in the four Parliaments and Assemblies of the UK. This aim is shared by UCB Pharma Ltd who have given the charity an arms-length grant to help achieve that outcome. Find out more about how we work with our corporate partners [**here**](#). The ROS is an independent charity, with the interests of patients, their families and the wider public at its heart. Our policy and research is editorially independent, with a view to influencing a wide range of audiences, including corporate partners. All agendas, reports, briefings and papers for meetings are prepared without external input.*