

APPG on Osteoporosis and Bone Health Thursday 24 February 2022 10:15am - 11:30am

MICROSOFT TEAMS

Attendees: Judith Cummins MP (Chair), Lord Black of Brentwood (Co-Chair),

Baroness Masham of Ilton, Lord Brownlow of Shurlock Row, Karin Smyth

MP, Baroness Quin of Gateshead

Apologies:

Minute Taker: Nikos Methenitis (ROS)

MINUTES

No.	Item	Action	Timing
1.0	Welcome from Chair		10:15- 10:20
	Judith Cummins MP, Chair of the APPG, welcomed all attending, and asked Parliamentarians to introduce themselves.		
2.0	Campaign for 100% Fracture Liaison Service coverage – upcoming opportunities in Parliament		10:20- 10:35
	The chair thanked the group for their support with last year's Inquiry into Fracture Liaison Services (FLS). Parliamentarians and the ROS will be campaigning on the report's recommendations throughout the year ahead.		
	Judith Cummins MP has put in for a Westminster Hall Debate on the FLS/APPG report findings.		
	Lord Black of Brentwood tabled an amendment to the Health and Care Bill calling for 100% coverage of FLS, which led to a well-attended debate in the House of Lords and a response from the Health Minister.		
	ROS has launched an e-petition on the Government's e- petition website and is urging supporters to sign. ROS will launch a similar e-petition in Wales to the Senedd soon.		

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	Lord Brownlow of Shurlock Row is looking to push for a further debate in the House of Lords in the coming months as a Question for Short Debate.		
	Craig Jones (CJ), CEO Royal Osteoporosis Society thanked parliamentarians for their work and pointed out that over the eight months of the operation of the APPG there were more mentions of osteoporosis in both houses than the previous eight years combined.		
	Karin Smyth MP added that Labour will be looking to bring debates on integration in both houses. Discussions on FLS will be part of this.		
	Judith Cummins MP suggested that parliamentarians in this group should meet in person to further discussions on campaigning and influencing opportunities.		
3.0	Craig Jones, CEO Royal Osteoporosis Society On the APPG's new inquiry into primary care for people with osteoporosis		10:35- 10:50
	Craig Jones (CJ) introduced the APPG's new inquiry into primary care for people with osteoporosis.		
	CJ an overview of the current national picture of osteoporosis. The APPG has chosen to investigate primary care as the FLS inquiry report showed gaps in knowledge, understanding and diagnosis of osteoporosis in primary care.		
	The primary care inquiry will follow similar framework to that of the FLS inquiry. A call for written evidence will be launched today. A patient survey will be commissioned. The APPG will hold three oral evidence sessions before 21 July 2022. Freedom of information requests will be issued to CCGs with particular focus on funding and a policy report will delivered to the Government in November.		
4.0	Carol Hufton, Patient Advocate On her experiences of primary care		10:50- 11:10
	Carol Hufton (CH) is an ROS Patient Advocate and member of the Stockport and South Manchester Osteoporosis Volunteer Group. CH told the APGG of her difficult experiences of osteoporosis and primary care.		

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No.	CH experienced inconsistency in knowledge and understanding of osteoporosis by GPs and a reluctance to refer for DXA bone density scans. It took over 5 years from her first fractures to receive a diagnosis of osteoporosis. Initial treatments CH received were not effective and caused painful side effects. CH had to seek out advice herself from a specialist before receiving a FRAX assessment and receiving more effective treatment. CH did however suffer a further vertebral fracture which was only discovered once she had moved to different DXA provider. CH felt these delays caused suffering to herself and family as well as a large cost to the NHS. As a volunteer with her local ROS support group CH has heard this story replicated many times, demonstrating a postcode lottery for effective diagnosis and treatment but also inconsistency from GPs within the same practice. Judith Cummins MP asked "What one change do you think would have made the biggest difference to the quality of care you received in primary care?". CH responded that should have been sent for a DXA scan in the first instance. Judith Cummins MP asked Dr Stephen Tuck (ST) "how education on osteoporosis can be improved for GPs". ST explained that there is variability of what GPs learn in training. This needs to be reviewed and standardised. Classification of osteoporosis as a long term condition would prioritise GP training on the condition.	Action	Timing
5.0	Dr Rosemary Leonard MBE, GP and health writer On osteoporosis and primary care		11:10- 11:30
	Dr Rosemary Leonard (RL) is a GP, journalist and a Trustee of the Royal Osteoporosis Society. RL outlined her experience of managing osteoporosis in primary care.		
	RL considered the current pressures for GPs including financial and target pressures from CCGs which discourage referrals for DXA scans. GPs are deterred from referring patients for DXA scans because it of the immediate financial cost. RL argued that the NHS needs ringfenced funding for FLS and DXA scans so that GPs are not discouraged from referrals.		
	Prioritisation of osteoporosis in primary care is a significant barrier to diagnosis and treatment. RL agreed that the classification of osteoporosis as a long term condition is needed to improve training and understanding of the		

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	condition by GPs. Low levels of vitamin D in the population are not being addressed. Data from RL's own practice indicates that 75% of the local patients have low levels of vitamin D. However, GPs are discouraged from prescribing vitamin D and instead asked to encourage patients to purchase it over the counter. Compliance is therefore low and there are issues around the variability of quality and dosage from commercially available vitamin D which is not as regulated as when prescribed.		
	Judith Cummins MP asked "If you could pull just one lever as a result of this inquiry, what would it be?" RL responded that this would be the categorisation of osteoporosis as a long term condition.		
	Baroness Masham of Ilton asked what preventative action could be taken, even in childhood, to tackle osteoporosis. RL emphasised the need to improve levels of vitamin D in children as well as exercise and balanced diets.		
	The APPG also heard from Nick Harvey of the University of Southampton and ROS Trustee, whose research has shown how people accrue the risk of developing osteoporosis across their lifetime. NH's research has shown that supplementing vitamin D in pregnant women leads to babies with higher bone mass. Bone health across the lifecourse is important in prevention and vitamin D is an example of this.		
	MEETING CONCLUDED AT 11:30		

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, Amgen, Stryker and the Medical Research Council Lifecourse Epidemiology Unit, University of Southampton, who have each 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.