

APPG ON DOWN SYNDROME
Annual General Meeting
Room W1, Westminster Hall

Tuesday 25 October 2022 2.30-3.00pm

Officers:

Chair Dr Liam Fox MP, Conservative (represented by Annabel Tall)
Vice Chairs Dr Lisa Cameron MP, SNP
Feryal Clark MP, Labour (sent apologies)
Flick Drummond, Conservative
Nick Fletcher, Conservative
Mark Logan, Conservative (sent apologies)
Seema Malhotra, Labour (sent apologies)
Virendra Sharma, Labour
Baroness Julie Smith, Lib Dem

Statement of purpose:

To campaign for equal access and provision to ensure equality and promote respect at all stages of life for people with Down syndrome.

Members:

Debbie Abrahams MP, Labour
Lord David Alton, Crossbencher (sent apologies)
Lee Anderson MP, Conservative
Siobhan Baillie MP, Conservative (sent apologies)
Douglas Chapman MP, SNP (sent apologies)
Caroline Dinéage MP, Conservative (sent apologies)
Colleen Fletcher MP, Labour (sent apologies)
Dame Meg Hillier MP, Labour
Ruth Jones MP, Labour
Rachel Maskell MP, Labour (sent apologies)
Gareth Thomas MP, Labour (sent apologies)
Stephen Timms MP, Labour
Lord Touhig, Labour
Matt Western, Labour

On behalf of the National Down Syndrome Policy Group:

Dr Elizabeth Corcoran
Nicola Enoch
Florence Garrett
Milli Prelogar

1. Election of Officers

- a. Out going Co Chair Matt Western led the meeting and conveyed thanks to the National Down Syndrome Policy Group for acting as Secretariat.
- b. The NDSPG thanked Matt and Dr Lisa Cameron for acting as Co Chairs and all that has been achieved since the launch of the APPG in May 2020.
- c. Dr Liam Fox was proposed as Chair, seconded by Virenda Sharma and duly elected
- d. Vice Chairs proposed and duly elected:
Virenda Sharma, Feryal Clark, Mark Logan, Dr Lisa Cameron, Seema Malhotra, Nick Fletcher, Flick Drummond and Baroness Julie Smith

2. Financial statement

Nicola Enoch advised the APPG does not have a bank account, so no income or expenditure to report. The NDSPG advised time given to provide secretariat equated to c£1,000 for the past year.

3. Lived experience – Employment

Florence Garrett spoke about the range of jobs she currently has.

Dr Corcoran advised only 6% of people with LD are in paid employment.

Dame Meg Hillier advised constituent in 6th form reports very limited opportunity, potential speaker at future event. Meg very keen to be involved, attended local work fair for folk with disabilities/challenging situations to which c380 attended with c250 receiving job offers.

Dr Lisa Cameron advised work undertaken as part of APPG for Disability with the speaker around Disability Confident Employers – need to encourage MPs to pursue.

Lord Touhig said Parliament should lead on this, advised 20 catering vacancies at Westminster. Great campaign – I am autistic, I am not unemployable.

Baroness Smith and Lord Touhig asked for briefings, so questions can be tabled, to raise the issue/keep on agenda.

Matt Western suggested Dr Fox to write to Health authorities to ask people with LD to be employed.

4. School census

Request from NDSPG to add Down syndrome to the school census – time sensitive – next due January 2023. Data needed to plan, evaluate provision and allocation of resources, useful to know where shortages of trained professionals required.

Once Education Minister appointed, suggested Dr Fox to meet to discuss. Concerns expressed around practical issues/time constraints. Issue raised around other conditions/syndromes – advised data collected for those who are autistic, visually impaired, deaf - precedent set.

5. NG Tube feeding

Moved from retroactive care to aggressive proactive care – but no protocol around tube being removed, no swallow test, transition to normal feeding, impact on speech and language too. Issues with delayed oral motor development and oral aversion, negative impact too on parental maternal health.

Dr Cameron suggested Liam write to NHS.

Ruth Jones advised not enough assessment for many babies – higher incidence when baby has Down syndrome, but relevant to others.

Next meeting expected to be March 2023

The NDSPG will be hosting an event the afternoon of **Tuesday 21 March** – World Down Syndrome Day to which members of the APPG are invited.