Minutes for the All-Party Parliamentary Group on Down Syndrome (APPGDS)
General Meeting: Tuesday 25th March 2025
Room N, Portcullis House 1.30pm – 3pm

Present:

Members

Damian Hinds MP (Cons, Chair)	Jen Craft MP
Andrew Cooper MP (Lab, Co-Chair)	Amanda Martin MP
Lee Baron MP	Graham Stuart MP

Other

Lucy Lee, Office of Damian Hinds	Kay Sammon, Office of Lee Barron
Vincent Masterson, Office of Graham Stuart	Neil Smith, Office of Andrew Cooper
Anna Robinson, Office of Jack Rankin	

Representing the National Down Syndrome Policy Group (NDSPG) Secretariat for the APPGDS:
Rachael Ross MBE
Ken Ross OBE

Representing the National Down Syndrome Policy Advisory Group
Florence Garrett, Chairperson, National Down Syndrome Advisory Group

Community Guest

Dr Ella Rachamim, Specialist Doctor in Community Paediatrics (Royal Free London NHS Community Trust) and co-author of the Barnet Combined Care Pathway for Children and Young People with Down Syndrome.

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.

Notes of the Meeting	Action
1.Welcome and preliminaries **1.1** Welcome from presiding Chair, Damian Hinds Damian Hinds (DH) welcomed all present to meeting of the All-Party Parliamentary Group on Down Syndrome. **1.2 Apologies:** Lord Alton, Dame Caroline Dinenage, Sir Liam Fox, Baroness Hollins, Lord Shinkwin **2. Minutes** **2.1** Members approved the minutes from the group's previous meeting on 14.01.25. The minutes are filed on the APPGDS website https://appg-ds.org/ once approved. **2.3** Damian welcomed new APPGDS members Lee Barron MP, Lorraine Beavers MP, Richard Holden MP, Perran Moon MP and Sam Rushworth MP.	

2.4 Officer election: Perran Moon MP was elected as the new APPGDS officer replacing Jack Abbott MP who is stepping down from his officer role but will continue to be a member. Chairs Damian Hinds (DH) and Andrew Cooper (AC) thanked Jack for his service and welcomed Perran to the group.	
3. Request from Jen Craft MP Jen requested signatures from the group to support a Backbench Business Committee Application regarding Down Syndrome Regression Disorder (DSRD). MPs at the meeting who agreed to support Backbench debate application: Damian Hinds, Andrew Cooper, Amanda Martin, Lee Barron and Graham Stuart.	
4. Actions from previous meeting and Debate updates **4.1 Update from Chairs on group's follow-up correspondence with Minister Kinnock and PPS.** The group has received a further communication from Minister Stephen Kinnock acknowledging concerns about the Down Syndrome Act Guidance. No solutions were put forward, and there was no offer to meet with the group. He reiterated that the guidance would be given priority and put out for consultation by the summer. AC said he would make a further request for the Minister to meet with the APPGDS and NDSPGand would update DH if a date was agreed.	**AC**
4.2 Update on request to meet Minister Timms Minister Timms attended the recent Down Syndrome Awareness Reception in Westminster and invited RR and DH to write to him with more information regarding ongoing issues with the Down Syndrome Act Guidance, with an offer of support. This has been done, and we await a response.	**RR, DH**
4.3 DS Westminster Debate Update 19.03.25 Graham Stuart (GS) was thanked for successfully securing a Westminster Hall debate to address concerns regarding the DS Act guidance. He, alongside other MPs, presented a compelling argument emphasising the widespread concerns associated with the guidance. MPs received a show of support on the day by individuals with and their families who attended. Although multiple questions were raised to the Minister during the debate, most did not receive a satisfactory response. GS to follow up. Link to transcript here: https://hansard.parliament.uk/commons/2025-03-19/debates/1A97B7F3-BBF2-4864-9078-AA222F52E72E/Down%E2%80%99SSyndrome	**GS**
4.4 Adjournment Debate – 28.03.25 -Down Syndrome Guidance Jack Rankin (JR) was thanked for securing an Adjournment Debate to discuss guidance issues Transcript here: https://hansard.parliament.uk/commons/2025-03-28/debates/D95596BB-629D-4A3F-98F3-9025DDE0B3DE/DownSyndromeAct2022LocalAuthorityGuidance JR follow up unanswered questions.	**JR**
Applying for debates: Minister Kinnock has said that the Down Syndrome Act draft guidance will be published for consultation by the summer (a further extension on the already extended spring term date). There is therefore a very short timeframe to resolve issues with the guidance.	
4.5 Meeting with the Secretary of State for Health and Social Care	

In the absence of securing a meeting with Minister Kinnock, it was suggested the group now requests a meeting with the SoS Wes Streeting. A request to all members of the APPGDS to speak with the SoS and request a meeting on behalf of the APPGDS.

4.6 Social Care Select Committee Request for Investigation

In addition, Sir Liam Fox has written to Layla Moran, a supporter of the DS Act and Chair of the Health and Social Care Select Committee, calling for an urgent investigation into the DS Act Guidance, citing failure of the government to uphold its commitments to the DS community, along with lack of government engagement. DH to contact Layla to follow up on behalf of the APPGDS.

DH

6. Assisted Dying Bill

6.1 Update Meeting with Kim Leadbeater (KL) and Kit Malthouse

(i) KL convened a discussion with DH, RR, and KR to address the concerns highlighted by the DS and LD Community in their widely endorsed open letter, which was signed by representatives from over 60 DS and LD organisations. During the meeting, it was noted that DH's proposed amendment was not accepted, as the DS Act guidance has yet to be issued. It was collectively agreed that KL would engage with Minister Kinnock to determine whether the amendment could be integrated pending the publication of the draft guidance by this summer. Additionally, there will be consideration to include a specific reference to the implications of the Assisted Dying Bill for individuals with Down syndrome in the DS Act Guidance, should the Bill be enacted. The possibility of incorporating Down syndrome in any relevant amendments where autism or LD are mentioned will also be explored.

DH

DH will resubmit DS amendment for Report Stage (completed).

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7. Awareness Reception Update

Florence Garrett, Chair of the National Down Syndrome Advisory Group, delivered a brief presentation at the NDSPG's 4th Annual Westminster Awareness Reception. This event, hosted by Damian Hinds and supported by the APPGDS, was attended by over 150 advocates and group leaders from across the UK, alongside MPs and peers and the NDSPG. Florence emphasised the crucial role of ongoing MP support in elevating the visibility of Down syndrome issues within Parliament. She extended her gratitude to DH for hosting, and to all attendees and those who shared the event on social media. The reception proved to be successful, resulting in an increase in MPs joining the APPGDS. Please refer to Attachment A.

8. Presentation by Dr Ella Rachamim, Specialist Doctor in Community Paediatrics (Royal Free London NHS Community Trust) and co-author of the Barnet Combined Care Pathway for Children and Young People with Down Syndrome

8.1 DH thanked Dr Ella Rachamim for her thought provoking presentation on the devastating impact of Down Syndrome Regression Disorder (DSRD), research updates and the importance of funding for research in the UK. See attachment presentation for more information. This tied in with Jen Craft MPs request (Item 3) and her speech for the Westminster DS Debate (Item 4.3).

8.2 Questions

Members asked a range of questions about DSRD and were invited to follow up with Dr Rachamim, should they require further information.

9. Future Meetings and Closing Remarks **Date of the next meeting APPGDS: Tuesday 3rd June 2025, Room N, Portcullis House, 13:30 – 15:00.**	**ALL SAVE THE DATE**

Attachment A:

National Down Syndrome Policy Group

Florence Garrett – National Down Syndrome Advisory Group

Reception Update

Hello, my name is Florence Garrett.

I have recently moved into my own flat in a supported living block of flats in Whitton.

In 2021 the National Down Syndrome Policy Group was founded by key DS organisations from across the UK. There are 15 officers, 5 of whom have Down syndrome. Soon after this I became an ambassador for the group.

Later that year, the National Down Syndrome Advisory Group was established. The Advisory Group is run by and for people with Down syndrome. It is made up from 120 people with Down syndrome from across the UK. The advisory group has four facilitators of which I am one and in November 2024 I was invited to become chair. We meet regularly to discuss through our lived experience, policy which impacts us, and we work in partnership with the NDSPG.

On 4th March this year, we held our 4th annual awareness reception in Westminster. It was a fantastic turnout, with over 150 advocates and Down syndrome charity leaders attending from all over the UK.

We were delighted that we had so many MPs who came along to the event and supported us so enthusiastically, and I want to say a particular thank you to Damian Hinds for hosting the reception.

The aim of the reception was to provide an opportunity for everyone to network and celebrate our achievements over the last year. It enabled some of us to meet our MP to discuss any challenges we face on a daily basis like accessing decent healthcare, work opportunities or adequate support in our daily lives.

Outcomes for children with DS are still poor. Still only 4.8% of adults with DS are in paid employment. During the pandemic people with DS were at an increased risk of catching COVID-19 due to increased risk of infection and barriers in accessing and understanding information and it can be up to 13 times more expensive to bring up a child with DS than a typical child.

Yesterday I returned home from New York where I was visiting my sister. This visit coincided with World Down Syndrome Day and I took the opportunity to attend the 14th WDSD Conference at the UN. This year's global theme is "Improve Our Support Systems".

Everyone needs support in one way or another, some more than others. People with Down syndrome have the same desires to make their own decisions, to positively contribute, to work, to be paid, to have meaningful relationships, to travel, to live independently, as other people in society, they just need more support to do this.

The importance of raising awareness about the challenges we face and the failings we still experience cannot be underestimated.

We hope you have managed to persuade more MPs to join the APPGDS so that you can be our voice in parliament and help us highlight the problems we face on a daily basis?

Finally, thank you to everyone who came along to support us on the day, and all those who raised awareness by posting our photos on social media.

We know how important our relationship is with MPs and the APPG on Down Syndrome, and we value it enormously. Please let us know what you need from us to make it as constructive and impactful as possible.

Thank you again for your support.

Florence Garrett
Chair, National DS Advisory Group