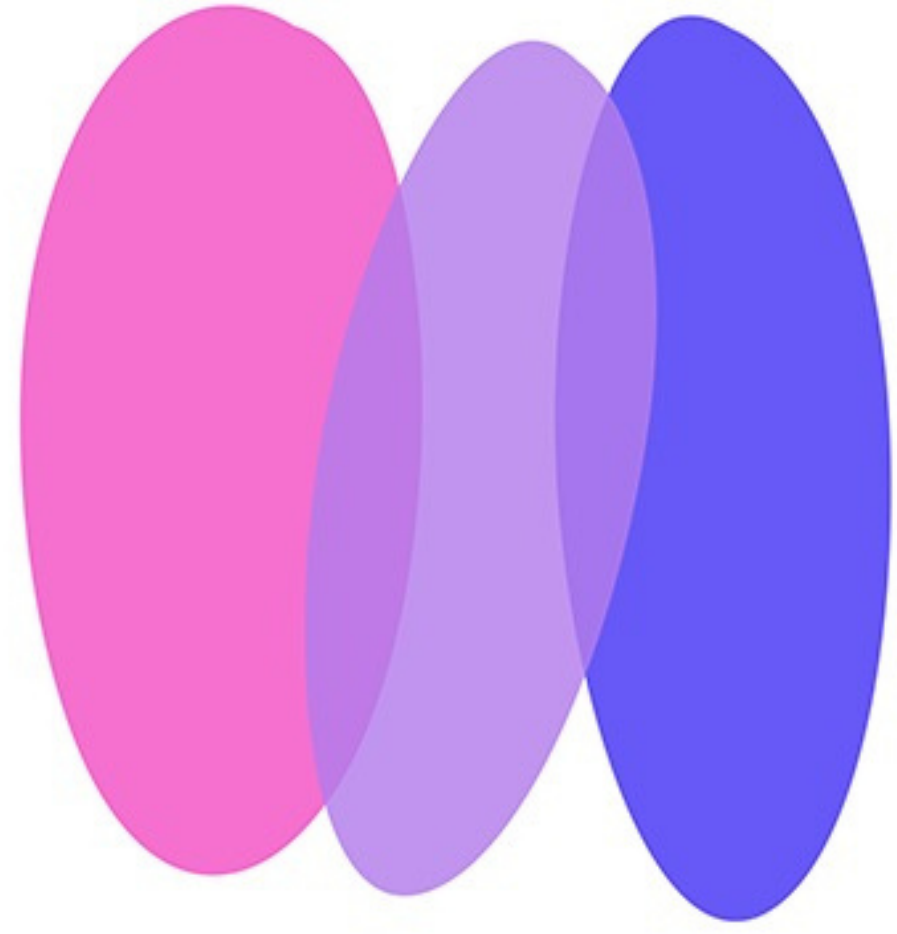


National Down Syndrome Policy Group



JANUARY 2022 NEWSLETTER

THE DOWN SYNDROME BILL

The Down Syndrome Bill introduced to Parliament last year by Dr Liam Fox MP passed its second reading on 26th November with cross party support and, very importantly government backing, meaning it will likely be added to the statute book this spring. We are hopeful this will be in time for World Down Syndrome Day so we can celebrate together.

Despite awful weather and a tube strike, many of you joined us to celebrate the Bill successfully passing the second reading. People came together from all across the country, from Lancashire to Cornwall and Hampshire to Hull.

We were joined by Dr Liam Fox MP who came to personally announce the result of the vote. We would encourage you to watch Dr Liam Fox MP addressing Parliament with questions and speeches from other MPs. Undoubtedly the Down Syndrome Bill has been so effective in raising awareness in Parliament and in the Civil Service more widely. [You can watch his groundbreaking speech here](#)

We also welcomed Heidi Thomas (creator and producer of Call the Midwife) and her husband Stephen McGann (Dr Turner in the series). Heidi's brother David died aged 15 after waiting too long for heart surgery. She spoke very movingly about his life and his enduring legacy - [you can watch her heartwarming speech using this link](#)

A WORD FROM HEIDI THOMAS

"Down Syndrome is a distinct condition that requires full acknowledgment, and better understanding, if those born with the condition are to thrive. We must now put all of our energy behind the next phase of the campaign, so that the Bill can be passed as law. As I know from personal and beautiful experience, loving someone with Down Syndrome changes the shape of your heart. It's time to take that love, and change the shape of the future."



MEETINGS AT PARLIAMENT

ALL PARTY PARLIAMENTARY GROUP FOR DOWN SYNDROME

On Wednesday 8th December the APPG for Down Syndrome, chaired by Dr Lisa Cameron MSP and Matt Western MP, met virtually for the second time.

Key points from the meeting -

- Dr Liam Fox MP updated the MPs on the progress of the Down Syndrome Bill.
- The MPs watched a video made by our founding officers with Down syndrome in which they expressed their hopes for the Bill. Heidi, James and Fionn asked the MPs for their support.
- They discussed how to encourage engagement from MPs
- MPs were reminded of the five main areas that the APPG will focus on - maternity care, education, employment, social care, health care/research.

SELF ADVOCATE MEETING WITH DR LIAM FOX MP

We are immensely proud of our founding officers with Down syndrome who have shown great commitment and who contribute regularly in our weekly meetings.

Prior to the meeting of the APPG, they were joined by several fellow self-advocates who have also worked so hard these past few months. They have attended meetings at Parliament, made promotional videos and undertaken numerous press interviews. They have done this with dedication, professionalism, great joy and humour. They are paving the way for others to follow and to bring the voice of all those with Down syndrome to the heart of Parliament. The awareness they have raised at such a high level in such a short time should be widely applauded.

Watch some of the team pose their questions to Dr Liam Fox MP on our YouTube Channel



UPCOMING EVENTS

ADVISORY GROUP

We are excited that our Advisory Group of adults with Down syndrome will soon begin. Through online meetings led by our founding officers Bethany, George, Heidi, James and me, we plan to;

- share information on the Down Syndrome Bill and what we are doing to make it law
- hear and record the opinions of those living with Down syndrome
- facilitate discussions about issues important to participants and how to make change

We'll be documenting and sharing what we learn as research reports, so that all our perspectives can shape policy.

Initially we'll have a series of three, monthly meetings. All adults with Down syndrome are welcome, and can attend with or without a supporter. Registration must be completed by January 14th.

For more information and to register interest follow this [link](#) or contact the project leader (that's me, Fionn) at Fionn.CrombieAngus@dspg.uk and please spread the word by sharing this [flyer](#)

Watch this very informative, short [video](#) where Fionn explains more about the group.

<https://ndspg.org/advisory%20group/>

WEBINAR

We hosted a webinar last year and many found this a useful way of finding out more.

We plan to hold these webinars monthly going forward with the next one on 26th January 2022. [Sign up using this link](#)

There will be opportunities to submit questions beforehand. This is a really good way of keeping informed about what is happening and hearing it first-hand from those working closely with Dr Liam Fox MP and his team.

Update from the National Down Syndrome Policy Group

The National Down Syndrome Policy Group invites you to the 2nd virtual meeting to discuss the Down Syndrome Bill as it passes through Parliament. The Bill, introduced by Dr Liam Fox had its successful 2nd reading on 26th November.

We will cover:

- Who are the NDSPG- recap
- The stages of a Private Members Bill and how it differs from a typical Bill
- Why a DS Bill and it's potential
- The new NDSPG advisory group
- How to get involved
- Any questions you may have - hot topics welcome

We would really like to meet with all support group leaders (and supportive members of the community and public) across the UK via a zoom meeting at 8pm on Wednesday 26th January 2022.

This is a 'once in a generation' opportunity that stand to improve the opportunities available to people with Down syndrome throughout their lifetime.

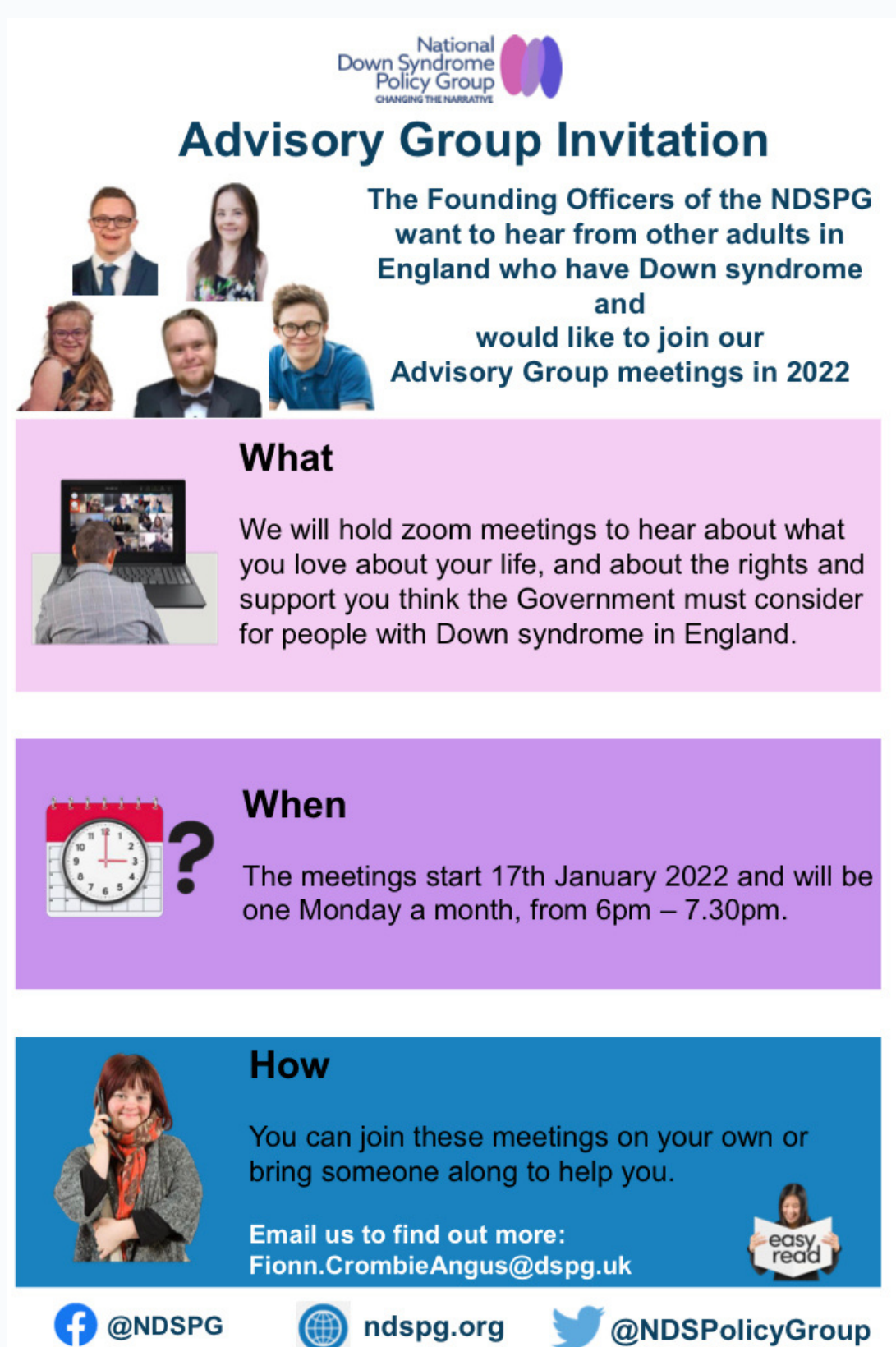
QUESTIONS AND COMMENTS

The best way to get in touch is via email contact@ndspg.org

For regular updates follow us on [Twitter](#), [YouTube](#), [Facebook](#) and be sure to join our mailing list - details on our new website www.ndspg.org

ADVISORY GROUP -

<https://ndspg.org/advisory%20group/>



The flyer is titled 'Advisory Group Invitation' and features the NDSPG logo at the top. It includes a photo of the founding officers and text stating they want to hear from adults with Down syndrome in England. The flyer is divided into three sections: 'What' (zoom meetings), 'When' (17th January 2022), and 'How' (join on your own or with a supporter). It also includes contact information and social media links.

Advisory Group Invitation

The Founding Officers of the NDSPG want to hear from other adults in England who have Down syndrome and would like to join our Advisory Group meetings in 2022

What

We will hold zoom meetings to hear about what you love about your life, and about the rights and support you think the Government must consider for people with Down syndrome in England.

When

The meetings start 17th January 2022 and will be one Monday a month, from 6pm – 7.30pm.

How

You can join these meetings on your own or bring someone along to help you.

Email us to find out more: Fionn.CrombieAngus@dspg.uk

[@NDSPG](#) [ndspg.org](#) [@NDSPolicyGroup](#)

THE NEXT STEPS

Private Members Bill

It is important to highlight that the Down Syndrome Bill is a Private Members Bill (PMB). Each year at the opening of Parliament and following the Queen's speech a ballot is created where if successful, MPs have the opportunity to propose a PMB.

We were very fortunate that Dr Liam Fox MP, despite being approached by several thousand other organisations, agreed to work with the NDSPG to sponsor a Down Syndrome Bill.

As a PMB is promoted by an individual MP the usual consultation process of a standard Bill of Parliament does not apply. The NDSPG worked with Dr Liam Fox MP's team to provide the initial drafting of the Bill which reflected the discussions with the APPGDS.

This draft was then amended by the government to secure their support. Without this support, the Bill would not have been successful.

This positive outcome was as a direct result of Dr Liam Fox MP's dedication to this cause and the tireless campaigning by the NDSPG and the wider Down syndrome community who joined together to show their support, lobby MPs and gain government backing.

We regularly update our [FAQ](#) section on our website.

We are very happy to try answer questions you may have - please email us at contact@ndspg.org

We may not have all the answers yet and so we respectfully ask for your patience in areas where there is still some uncertainty.



We support the ambitions of the new [#DownSyndromeBill](#). We look forward to seeing the detail once it is published. Congratulations to those involved & thank you to [@LiamFox](#) for taking this step. We look forward to working with you & your team in the future. [@NDSPolicyGroup](#)



We are really pleased about the [#DownSyndromeBill](#) and the brilliant campaigning by some of the [#DownSyndrome](#) community. It will make local authorities, places of healthcare and schools think about people with Down's syndrome when creating services.



Thanks to all my colleagues from across the House for the warmth of the support for the [#DownSyndromeBill](#). In this House we hold the power to empower, and that is what this Bill does for those with [#DownSyndrome](#). I urge them to use their voices and know that all are behind them.

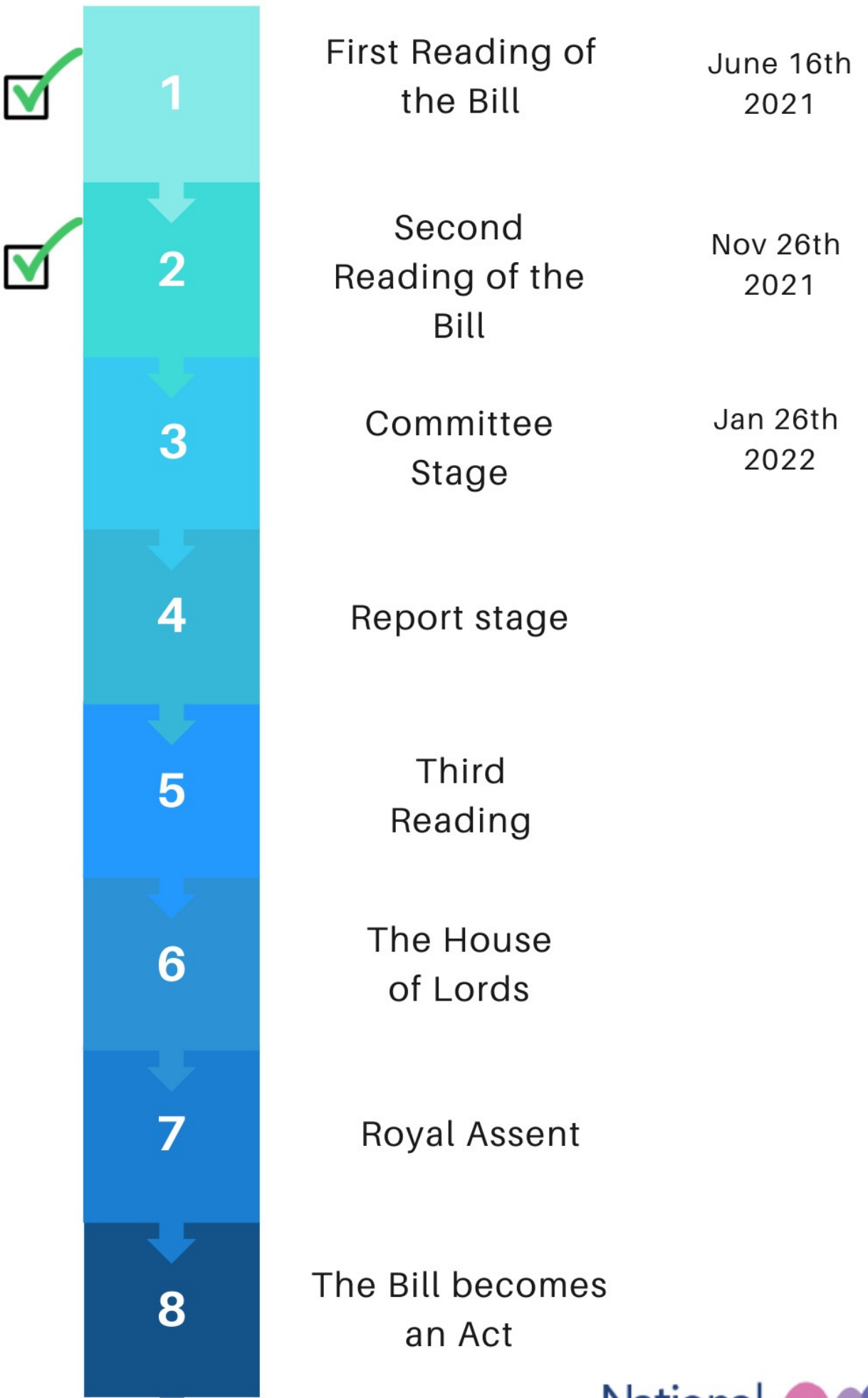


Elliot Colburn MP · 26/11/2021
A FANTASTIC afternoon with Lucienne Cooper, Charlotte, and campaigners outside Parliament to celebrate the 2nd Reading of the [#DownSyndromeBill](#), of which I am a co-sponsor.

Huge congratulations to everyone for all their hard work so far. 🎉



TO BECOME UK LAW, THERE ARE 8 STEPS THE DOWN SYNDROME BILL MUST COMPLETE:



*dates are subject to change by Parliament

