

# Invitation to take part in the Advisory Group of the NDSPG

from Fionn Crombie Angus





Hello Everyone.

My name is Fionn Crombie Angus. I am a researcher, and I have Down syndrome.

I'm inviting you to join the Advisory Group for the NDSPG (which stands for the National Down Syndrome Policy Group). The NDSPG are working with the UK government to support people with Down syndrome to have good lives.



This Advisory Group will hold meetings for people with Down syndrome to share and record their views with the NDSPG.

The NDSPG will use what you tell us at the meetings to help the government with the Down Syndrome Act so people with Down syndrome get the same opportunities as everyone else.



The Advisory Group meetings are usually held on Zoom from 6:00 – 7:30 pm on the third Monday of the month.

Sometimes we may have more meetings, depending on what work we decide to do.



During the meeting we will:

Tell you about the Down Syndrome Act

Collect your opinions about living life with Down syndrome

Have an open discussion, and try our best to answer questions



We plan to share what we all learn together.

I and other researchers plan to write this up as a research project.

The write-up won't mention your name, so, we will only share something you said, not who said it.



We also plan to make a movie about the process of creating the Down Syndrome Act, and we're going to use some video clips from our meetings to help tell the story.

You might appear in our movie, if you agree to. You'll get to choose, either way.

And, if you decide at some point that you don't want to continue, no problem – you can drop out any time.



I am the co-ordinator of the Advisory Group and a Founding Officer of the National Down Syndrome Policy Group.

As the Co-Chair of an International Inclusive Research Group, I've been involved in a lot of research, and a lot of training about research, but I'm still learning.

My dad will be helping me. You might want to have your dad (or whoever you choose) help you during the Zoom meetings, but only if you want to.



If you do bring a helper, your helper will be in the Zoom call just to help you.

They can speak up in the meeting (because some of us rely on people who really know us well to help say the things we want to say, and you can do that here), but the helper shouldn't be sharing their own opinions about things - only people with Down syndrome are considered participants.



If you are attending our Zoom meetings independently, and you don't know how to do Zoom things like joining a meeting, changing your name, muting and unmuting, I can show you how ahead of time. Just write me an email.



The meetings will be co-facilitated by 5 members of the facilitator team who have Down syndrome.

Those are James, Heidi, Florence, Ed and me.

You'll meet some of the other members of the NDSPPG who don't have Down syndrome (like my dad) because they'll be there to lend a hand.

Feel free to write to me with any questions.



To let us know that you want to attend the meetings, all you have to do is email me with your completed Consent Form, and I'll send you a Zoom link to the next meeting.

I'm really looking forward to meeting you all.

Warm regards, Fionn Crombie Angus

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