

Teddington's Down's Syndrome Association

The
Strategy
Unit.



Overview

Reference: 02

Location: Teddington

Group: People with
Down's syndrome

Initiative type:
Information

Contact

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Top Tip

Keep talking and pushing and try to reach people. Think about every possible channel and available opportunity to get the message out.

Why is this important to us?

Evidence shows that mortality rates for COVID-19 were significantly higher for people with Down's syndrome. The vaccine is new so some people with Down's syndrome were anxious about its safety, side effects and whether people with Down's syndrome were part of the clinical trials. They required support to manage expectations around the vaccine. We were aware some people had not received a letter telling them they were on the Clinically Extremely Vulnerable List and might miss priority vaccine access. We also knew that others may find information inaccessible and might struggle with the environment of Vaccine Centres.

What are we doing?

We are an information providing organisation. We have a website, use Twitter Instagram, YouTube and we have a big presence on Facebook. We provide easy read versions of important information, We filmed somebody who has Down's syndrome interviewing Roger Banks (Head of LD services at NHSE) asking a series of vaccine related questions. For reassurance, (and with their permission) we shared pictures of people with Down's syndrome getting their vaccine. We also shared individual experiences of getting the vaccine. We deliver free weekly webinars for family carers. Our teams work at an advocacy level trying to support people who have not received an invitation for the vaccine.

Who is involved?

We have a small communication team including a Comms Manager, Assistant and Social Media Officer. We also worked with NHSE to produce Q&A videos and received regular updates from them which we cascaded at our weekly webinars. We have to monitor posts and keep an eye on questions and comments.

What works for us?

We have to keep updating the information on our website and social media. We have occasional posts from anti-vaxxers so we need to make sure we respond to them with the evidence or direct them to JCVI resources. We don't just rely on social media channels as some people might not be on social media. We also wrote letters to everyone on our mailing list, advising people with Down's syndrome that they are on the priority list. **We have received positive comments in the chat box at our webinars. We often receive emails giving thanks for the information and it is lovely to hear when people have got their vaccine. The weekly webinars were very popular - 600 people signed-up from around the UK, they were so desperate to receive information.**

NHS England

NHS Improvement