

By email to: jcvi@phe.gov.uk

To Members of the Joint Committee on Vaccines and Immunisation

Contact, is the UK charity for families with disabled children. We strive to be there for every family whatever their child's condition or need. Each year we help more than 150,000 families with the best possible information and advice.

Families we support have been severely affected by Covid-19. Not only have they contracted the virus, they have also been much more severely impacted by measures taken to reduce the risk of the virus spreading. Lockdown has left most without support, families are exhausted and continue to be concerned for the safety of their clinically extremely vulnerable children.

As a result Contact is campaigning for priority access to Covid-19 vaccines for clinically extremely vulnerable children. Our campaign petition has been supported by 3454 families.

We are asking members of the committee:

- To prioritise clinically extremely vulnerable children for Covid-19 vaccines when they are licensed for use in children.
- Provide information on when a vaccine for clinically extremely vulnerable children will be rolled out.
- Expand your guidance on which children can get unlicensed use of the vaccine and set up a process on how families and doctors can get unlicensed use of Covid-19 vaccines.

Contact is publishing research this week about access to Covid-19 vaccines based on the responses from 3000 families with clinically extremely vulnerable and other disabled children.

The results offer a unique insight into access amongst this seldom heard group and some really positive evidence on take-up as a direct result of the JCVI recommendation that unpaid carers be added to the priority list: 86% of parents with disabled children have been offered a Covid-19 vaccine, 2 in 3 as an unpaid carers.

The results also shows most (70%) want their shielding or disabled children to have a Covid-19 vaccine when it has been licensed for use in children. Importantly, 1 in 10 would like access to a covid vaccine unlicensed right now, but only a handful (1.5%) have been successful in getting it unlicensed so far.

Whilst most clinically extremely vulnerable adults have now been offered a Covid vaccine, children with the same conditions are waiting at home with no idea when their turn might come.

Our research shows there is a lot of confusion about unlicensed use of the vaccine in children and this is leading to an inconsistent approach being applied where two children with the same condition – one has receives it unlicensed and another doesn't. Access often depends on the determination of parents rather than a fair process

Contact has been in touch with many parents like Kelly Hughes who hopes to be getting an appointment for her 15-year-old daughter Sophie's vaccine soon, but only after several months of fighting for it. Sophie has Mitochondrial disorder – she has a tracheostomy and high medical needs.

They have been shielding since March 2020. They have kept Sophie's younger sister at home too. It has had a huge impact on all their lives with no end in sight. When Kelly saw information about getting vaccines off licence for children in exceptional circumstances she started making enquiries. That was back in January and last week the metabolic specialist agreed she can have it. They are now waiting for correspondence from GP. She feels it is a difficult process because no one is sure where the responsibility of it lies and this needs to be communicated better.

Other key findings from our research into vaccine access includes:

- 79% of disabled youngsters (aged over 16) will have the vaccine when offered it, 18% are not sure, most due to being scared of needles or worried about impact on condition, but only 3% said they wouldn't have the vaccine when offered.
- 58% of eligible disabled youngsters (over 16) have offered a Covid vaccine
- 11% of eligible young carers have been offered a covid vaccine, needed to protect their disabled siblings
- Less than half of couples have both had a covid vaccine as unpaid carers, needed to protect their clinically extremely vulnerable children
- 60% of those that tried to register as an unpaid carer with their GP faced problems

While we wait for vaccine approval for children it is essential that all family members in households with clinically extremely vulnerable and other disabled children are vaccinated as soon as possible. Therefore, we urge the committee to amend existing guidance on 'main' unpaid carer to include all adults (including eligible young carers) regardless of the condition or disability of the child. This will offer the most protection until a vaccine for them is available.

I look forward to your reply so we can get information out to families we support.

If your team require further information or assistance, please contact una.summerson@contact.org.uk or 07725000728.

Yours faithfully,



Amanda Batten, CEO Contact, the charity for families with disabled children
And 3454 families with clinically vulnerable and disabled children who have supported our access to covid vaccine campaign