

Initial Report

Knowledge and Awareness of COVID-19 Vaccine Information

Families Know Best - March 2021

1 - What is your place of residence?

Answer	%	Count
New Castle County, DE	46.15%	12
Kent County, DE	23.08%	6
Sussex County, DE	15.38%	4
Other - Pennsylvania Resident	11.54%	3
Other- New Jersey Resident	3.85%	1
Other- Maryland Resident	0.00%	0
Total	100%	26

2 - What is your child's disability or health condition?

Answer	%	Count
Attention Deficit Hyperactivity Disorder	3.85%	1
Autism Spectrum Disorder	34.62%	9
Cerebral Palsy	0.00%	0
Diabetes	0.00%	0
Down syndrome	3.85%	1
Epilepsy	0.00%	0
Traumatic Brain Injury	0.00%	0
Other (please specify): (see next slide)	23.08%	6
Multiple disabilities (please specify): (see next slide)	30.77%	8
Hearing Impairment/Deaf	3.85%	1
Visual Impairment/Blind	0.00%	0
Total	100%	26

2 - What is your child's disability or health condition? (continued)

Other (please specify): - (answers appear as provided by survey participants)

Conduct disorder

Muscular dystrophy, Trached and vented, chrons, hypontia

Type 1 Diabetes

Depression

cdk 13

mild intellectual disability

Multiple disabilities (please specify): - (answers appear as provided by survey participants)

Cerebral palsy, epilepsy, developmental delay

Extra gene; mental and physical disabilities

rare genetic dx, CP, epilepsy, etc

Epilepsy and ADHD

Attachment Disorder, Conduct Disorder, ADHD

Rett Syndrome

Down Syndrome & Intellectual Disability and Autism Spectrum

Cp, epilepsy

3 - What is the age of your child?

Answer	%	Count
0-4 years old	0.00%	0
5-11 years old	26.92%	7
12-21 years old	69.23%	18
over 21 years old	3.85%	1
Total	100%	26

4 - Please identify yourself.

Answer	%	Count
Mother	96.15%	25
Father	3.85%	1
Legal Guardian	0.00%	0
Foster Parent	0.00%	0
Other (please specify):	0.00%	0
Total	100%	26

5 - What is your race/ethnicity? (Check all that apply)

Answer	%	Count
White	70.00%	21
Black or African American	16.67%	5
Hispanic, Latino, or Spanish Origin	3.33%	1
Asian	6.67%	2
American Indian or Alaska Native	0.00%	0
Native Hawaiian or Pacific Islander	0.00%	0
Other (please specify):	3.33%	1
Total	100%	30

Other (please specify): - (answers appear as provided by survey participants)

My race is white; my son is Asian.

6 - Do you consider your child's health insurance coverage to be adequate to meet your child's needs?

Answer	%	Count
Yes	69.23%	18
No (please explain below):	30.77%	8
Total	100%	26

No (please explain below): - (answers appear as provided by survey participants)

Does not cover extra support or treatment he needs, like 3 dental visits a year instead of 2, etc.

Too many prior authorizations needed for everything, and providers are unwilling to do prior authorizations

no providers in the area who accept Medicaid . cutting in-home services too

Even with Medicaid as a secondary insurance, I have found some meds are not covered. Also home nursing is an issue.

The insurance we had did not cover any of a very expensive therapeutic program that we decided was best for him.

My child's PRIMARY health insurance does not cover her needs; Medicaid always picks up the balance.

It seems we will be fighting nursing hours from now on for a child with intensive medical needs.

I think we are not offered everything available to treat this because our state insurance

7 - Have you tried to access information and resources related to the COVID-19 vaccine?

Answer	%	Count
Yes	69.23%	18
No (see question #10 for follow-up question)	30.77%	8
Total	100%	26

8 - Were you able to access needed information and resources about the COVID-19 vaccine?

Answer	%	Count
Yes (see below for follow-up question)	94.44%	17
No	5.56%	1
Total	100%	18

9 - What are your sources of information regarding COVID-19 vaccine? (Check all that apply)

Answer	%	Count
State of DE Website	33.33%	12
CDC Website	41.67%	15
Specific State Agency website. Please specify.	2.78%	1
Other Federal website. Please specify.	0.00%	0
Other source. Please specify.	5.56%	2
Medical Provider	16.67%	6
Total	100%	36

10 - What were the barriers to accessing the needed information and resources relating to the COVID-19 vaccine? (answers appear as provided by survey participants)

What were the barriers to accessing the needed information and resources relating to the COVID-19 vaccine?

I really have not yet tried to access vaccine information, but plan to do so for myself in the near future now that anyone over 16 is eligible.

n/a

No barriers

Don't want it

N/a

Did not want to access info for my child just yet.

I had to wait on them even though she should have qualified in 1a.

History ...theres no telling what the effect are going to be.

11 - Is your child eligible to receive the COVID-19 vaccine?

Answer	%	Count
Yes	34.62%	9
No	42.31%	11
Don't know	23.08%	6
Total	100%	26

12 - Are you interested in obtaining the COVID-19 vaccine for your child, if/when your child is eligible?

Answer	%	Count
Yes	73.08%	19
No	26.92%	7
Total	100%	26

13 - What are your reasons for not wanting to have your child vaccinated? (answers appear as provided by survey participants)

What are your reasons for not wanting to have your child vaccinated?

I dont want to give my child stuff we dont knoq how it will effwct humans in the future or even at the tike because theres no history. We dont know

I do not wish to share

I'd like to see what happens in a longer setting

No long term studies

Not been out long enough

Not enough research done on the vaccine yet

Too many unknowns

14 - Is there any other information you would like to share in regards to resources and information available to you regarding the COVID-19 vaccine? (answers appear as provided by survey participants)

Is there any other information you would like to share in regards to resources and information available to you regarding the COVID-19 vaccine?

Wish more information was available and providers putting shots in arms reviewed your paperwork more thoroughly!

No

Not at this time.

No

n/a

research of vaccine on rare diseases

No

No

No

No

My daughter has received the first shot of Moderna vaccine.

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Is there any other information you would like to share in regards to resources and information available to you regarding the COVID-19 vaccine?

No

My child has already received the vaccine and had no side-effects.

none

The Delaware gov't website is good, as is the CDC's.

No

N/a

None

No.

It was very difficult to find a place offering the Pfizer vaccine since my son is 17 and could not get the Moderna option. Luckily our school (HMS School for Cerebral Palsy in Philadelphia) made an arrangement with CHOP and they prioritized our students for the vaccine. My son has already had both doses.

What are the side effects of the vaccine on children 10 and under?

14 - Is there any other information you would like to share in regards to resources and information available to you regarding the COVID-19 vaccine? (answers appear as provided by survey participants)

Is there any other information you would like to share in regards to resources and information available to you regarding the COVID-19 vaccine?

I am worried our decision will affect her ability to receive needed medical care. She is no more contagious than any other human on the planet. This would be a form of discrimination. It would be infringing on my rights.

No

Give people the options

I can't think of anything else relevant.

We'd more information that is understandable and stated plainly. The vaccine insert is hard to understand and relate to how it applies to different sub-groups