

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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THE COVID-19 VACCINES



The COVID-19 Vaccines are becoming available to more people every month.

For nearly a year, the world has faced the ever-growing impact of the SARS-CoVi-2 (COVID-19) pandemic. Everyone's experience has been both similar and different. Parents dealt with suddenly managing their children's education from home, some have felt isolated; some have worked overtime, while others faced job loss; and we all wondered what happened to the toilet paper! These dramatic changes to our daily routine have been hard, but others faced the devastation of losing a loved one to the virus.

At last, we now seem to be seeing some numbers fall as vaccines have now arrived on the scene, and social distancing and masking prove to be vital components for containment. The currently approved vaccines have been put into use in record time, but there is a long wait for many, along with more questions. There is so much information, misinformation, and confusion, it is no wonder people are curious, nervous, scared, skeptical, or excited all at once.

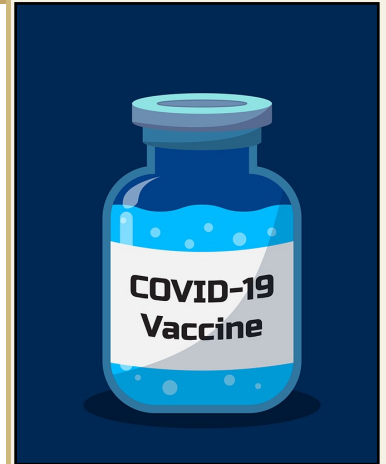
What do we know about these vaccines, and what facts should be reviewed before making the decision to be vaccinated? We hope this article can help navigate some of these questions and help our patients and readers to have an informed view when making their own choice.

What vaccines are available?

Currently (as of February 2021) there are two vaccines that are being administered in the United States under what is called an [Emergency Use Authorization \(EUA\)](#). This means the vaccine has not yet received full FDA approval, but all the data appears that the vaccine will be safe and effective, and it can be used immediately in an effort to prevent illness and death. Other products, such as test kits and potential medications for those sick with the virus have also been given this authorization throughout the pandemic.

A [vaccine by Pfizer-BioNTech](#) was given this authorization on December 11, 2020, and another [vaccine by Moderna](#) was given this same approval a week later on December 18, 2020. Both are called [mRNA vaccines](#), which stands for messenger RNA. This is a new kind of vaccine that takes a different approach than vaccines in the past. Other vaccines use a bit of weakened or inactive virus or viral protein to trigger an immune response, but mRNA vaccines bring the message to our cells about how to make a viral [protein that triggers the immune response](#). While this type of vaccine is new, the technology has been studied and applied for many years.

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What do you know about the new vaccines available for COVID-19? We aim to answer some of the big questions.

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Find us on Facebook, Twitter, and our website for frequent updates on news and events.



Go to facebook.com/ColoradoHTC



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Website: Go to

medschool.cuanschutz.edu/hemophilia-thrombosis



Email:

HTC.Newsletter@ucdenver.edu

WHAT'S IT LIKE TO GET THE VACCINE?



Dr. Beth Warren getting one of her vaccines.

Many of our HTC clinical staff were among the first people in Colorado who were eligible to receive the vaccine. We asked them what it was like to get the vaccine and what they wanted to share with patients about their experience.

While not a scientific survey, the consensus was that most had some mild side effects after receiving the vaccine. These side effects ranged widely. Some said the vaccine hurt a lot when being injected, others said they didn't even realize they had been given the shot. A number of people reported feeling achy and bad for one to two days, and a few had no side effects at all. Several people indicated that the second shot resulted in more noticeable side effects than the first, but some said it was about the same. Most indicated their symptoms were mild, such as being tired, or having a sore arm.

Staff members who have received the vaccine expressed that getting the vaccine made them excited and hopeful for the years to come. It was powerful for our researchers to get to be a part of something that was the result of research and trials done by many volunteers around the world.

Though most of our clinical and pharmacy staff has been vaccinated with both doses, we are still using extreme caution in our clinic. We are continuing to have restricted access to the clinic, using our standard PPE, continue to have increased cleaning of all surfaces, as well as maintaining social distancing measures.

Please contact us if you need to be seen in clinic, via tele-health, or have questions about the vaccine.



Kristi Norton and Julie Smith with the Children's Hospital "Elves" getting one of their vaccines.

Pediatric Stroke Parent Support Group

VIRTUAL ZOOM Meeting

**Tuesday
Mar 9, 2021
6:30-7:30 pm**

A reminder that our [Pediatric Stroke Parent Support Group](#) is now meeting online. We will continue meeting online a while longer to keep everyone safe.

We hope you can join us for our next online meeting on **Tuesday, March 9, 2021 from 6:30-7:30 pm.**

This group meeting welcomes everyone in the family to join. Your child does not need to be treated at our center to attend.

To join, please RSVP by contacting us at strokesupport@ucdenver.edu or (303) 724-8520. Follow us on Facebook for the latest on our meetings at www.facebook.com/Colopedstroke.



THIRD NATIONAL PATIENT SATISFACTION SURVEY TO LAUNCH IN SPRING 2021

How satisfied are you with your HTC services? HTC patients and caregivers throughout the US are invited to tell us this Spring. The Third National Patient Satisfaction Surveys (PSS) is set to begin going out to bleeding disorder patients around the country soon. This survey will be sent to our bleeding disorder patients who received care at our HTC last year asking how their experience was.

Each survey will be anonymous but will allow our center to get much needed feedback from patients about their care. Nearly all HTCs had to make major adjustments in 2020 due to the COVID-19 pandemic. In response, questions have been added to this survey asking patients for feedback on tele-health as well as in-person care.

Please watch for more information on how to participate in the next survey, which is slated to begin from our center in March. The survey is brief and will be available in both English and Spanish. Those who received care from their HTC in 2020 are encouraged to fill out the survey online once it goes live in March. Paper surveys will be mailed out to families as well. For questions, or to learn more about the earlier surveys, please go to htcsurvey.com.

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You will need two shots, given several weeks apart for the currently available vaccines.

Both of these vaccines are intended to have two shots: the [Pfizer-BioNTech vaccine](#) 21 days apart, and the [Moderna vaccine](#) 28 days apart. There are several other vaccines using different technologies that are currently in large-scale, Phase 3 trials and may become available as the year

progresses. Some may require only one shot, so be sure to check with your provider when receiving a vaccine to know which one you are receiving.

Are the mRNA vaccines safe?

Both the Pfizer-BioNTech and Moderna vaccines have had extensive trials and testing that not only show low risk but both have been shown to be very effective in preventing severe COVID-19 illness. Evidence from clinical trials showed that the [Pfizer-BioNTech vaccine was 95% effective](#), and the [Moderna vaccine was 94.1% effective](#). Like all vaccines, there will be small risks. The most notable risks to these vaccines are potential allergic reactions. When you receive this vaccine, you will likely be asked to wait for 15-30 minutes to watch for any sign of allergic reaction. People who have had severe allergic reactions (anaphylaxis) to vaccine components should not get a vaccine without discussion with a physician familiar with their health. Talk to your doctor about allergic reactions if you fall into this category.

[Myths saying that this will alter your DNA are false](#). The mRNA from these vaccines never enters the nucleus of your cells where your DNA is stored, and does not integrate into your genome. As soon as the mRNA delivers the message to your body to create a spike protein (that is designed to help your body recognize the virus), the mRNA is broken into harmless pieces.

What about side effects?

Almost all vaccines have what most would call a 'side effect', but that would be more correctly described as an immune response reaction to the vaccine. This is a good and normal thing, indicating your body is creating protection against the virus. Normal side effects that you should expect are pain, swelling, or redness in the arm where you were given the shot. You may also experience fever, chills, body aches, tiredness, or a headache. These side effects usually start within a day of getting the vaccine and may feel like you have a cold, and may affect your ability to do daily activities. Most reported side effects were mild and should go away within a few days. Not all people who get the vaccine experience these side effects, and the vaccine still works if you do not experience noticeable side effects.

Can the vaccine make me sick with COVID-19?

[The answer is no](#). None of the vaccines currently available or even in development use the live virus. Because of this,

none of the vaccines can give you the virus or give you the illness, COVID-19. You may have side effects that appear as if you suddenly feel sick, such as a fever, chills, or aches, but this is your body responding to the vaccine in a positive way.

It takes a few weeks for your body to build all the protection it needs to prevent COVID-19, so it is also possible for someone to get infected just before or just after vaccination. This is why it is still very important to keep using preventative measures such as social distancing, masks, and hand washing, even if you have just been vaccinated. Because the COVID-19 virus and the vaccines are new, the exact time of how long it takes to be immune, and how long that lasts is still being studied. Vaccinated people still need to adhere to masking and social distancing until this is known. Widespread vaccination seems to be the best way of keeping the pandemic in check, and even if it does not prevent all illness it [may lower the risks and dangers of the disease](#).

If I have a bleeding or clotting disorder, can I get the vaccine?

[Yes!](#) The COVID-19 virus does not attack those with bleeding or clotting disorders at any higher frequency than others who do not. This means that while those with bleeding disorders have a rare condition, they are not considered a priority unless they fall into the categories of people currently getting the vaccine (such as those who are working in healthcare, or those 65 years and older for example). Either of the currently available vaccines will work in a person who has a bleeding disorder just the same as those who do not. Those who also have other conditions, such as hepatitis C, HIV or other circumstances that require the use of immunosuppressive agents, can still get the vaccine. If you have questions or concerns please talk with a physician who knows you and your health well.



Treat the COVID-19 vaccines much like you would any routine vaccine.

Just as with regular vaccines for our bleeding or clotting disorder patients, normal precautions should be taken when receiving the COVID-19 vaccines. Those with bleeding disorders may want to infuse with factor replacement products prior to, or right after vaccination and apply pressure for 10 minutes after receiving the vaccine. If you normally would use an ice pack on the site of vaccination, you may do so. The area of injection should be monitored for hematoma formation immediately and by self-inspection 2-4 hours after. Normal discomfort after injection is to be expected as are the regular side effects. Adverse reactions should be reported to your doctor, and any allergic responses should be reported immediately. [Other questions about vaccines with a bleeding disorder can be found here](#).

Please reach out to us at the HTC if you have more questions about the vaccines and if it is safe for you to get one. We are happy to help provide guidance for your particular case.

RECENT HEADLINES

These are a few of the headlines that we've recently featured on our Newsroom page or on Social Media.

Study Shows Esperoct Highly Effective as Prophylaxis Treatment for Hemophilia A

BioMarin Shares Positive Data for valactocogene roxaparvovec, Gene Therapy

CSL Behring Issues Voluntary Recall of Mononine

Study Suggests Eloctate Induces Faster Immune Tolerance than other Regimens

Phase 3 Trial Shows Sustained Drop in Bleeding Rates for Roctavian, Gene Therapy for Hemophilia A

We maintain a newsroom page at our website with a list of the news we feel may be of interest to our patients and families. Go to medschool.cuanschutz.edu/hemophilia-thrombosis/resources/newsroom to read more. We also share news on our [Facebook](#) and [Twitter](#) accounts.

UPCOMING EVENTS

Mark Your Calendars:

Please note. These dates may be tentative and subject to change due to the COVID-19 pandemic and restrictions. Please check appropriate websites for confirmation of events.

March is Bleeding Disorders Awareness Month

Mar 1-5: NHF Washington Days—Virtual

Mar 9: Pediatric Stroke Parent Support Group—Virtual

Mar 11: NHF CO Women's Paradise Paint Event—VIRTUAL

Mar 18: NHF CO & RMHBDA Teen Advocacy Group—VIRTUAL

See more at our Events Page on our website:
medschool.cuanschutz.edu/hemophilia-thrombosis/resources/events-calendar

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Pharmacy Main: 303-724-0168

or toll free at 888-724-7427

Web page:

medschool.cuanschutz.edu/hemophilia-thrombosis

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