



Featured CF Artist — Kinsley

Kinsley is an 8 year old girl who loves life and anything pink or sparkly! She's spunky and a force to be reckoned with. One minute you can find her outside horsing around with her dad and brother. The next minute she's inside asking mom for makeup and a dress to have a tea party with all the glitz and glam! Anyone who knows Kinsley loves her unique personality and in turn feels the love and compassion she has for others!

*Would your child like to be featured in an upcoming newsletter?
Email charlotteCFfamilies@gmail.com for info!*

Stay Safe During the Holidays!
SPECIAL VIDEO FROM OUR CARE TEAM



Our CF Care Team has created a special holiday greeting to remind all our families to **STAY SAFE!** You can watch the video online at:
charlottecffamilies.org/updates/happy-holidays-from-our-care-team

Don't Forget Your Flu Shot!

In people with CF, the flu can lead to a severe lung infection, like pneumonia. If you have the flu, you may feel worse than you do with a typical lung infection or pulmonary exacerbation. Contact your CF care center or doctor's office as soon as you feel flu-like symptoms. Antiviral medications used to treat people for the flu are most effective if taken within 24 hours of the start of symptoms. These drugs may help lessen your symptoms or how long you are ill.

WHAT IS THE DIFFERENCE BETWEEN INFLUENZA (FLU) AND COVID-19?

Influenza (Flu) and COVID-19 are both contagious respiratory illnesses, but they are caused by different viruses. COVID-19 is caused by infection with a new coronavirus (called SARS-CoV-2) and flu is caused by infection with influenza viruses.

REDUCING THE RISK: THE FLU SHOT

The flu vaccine or "flu shot" can reduce the risk of getting the flu by helping the body fight off or increase its immunity to the flu virus. It is best to get the flu shot early since it can take around two weeks after vaccination for the body to build up its immunity to protect itself against the flu virus.

The best time to get the flu shot is in September through October, but getting vaccinated in December or January is still helpful as flu season can last until spring.



Questions About COVID-19 Vaccine

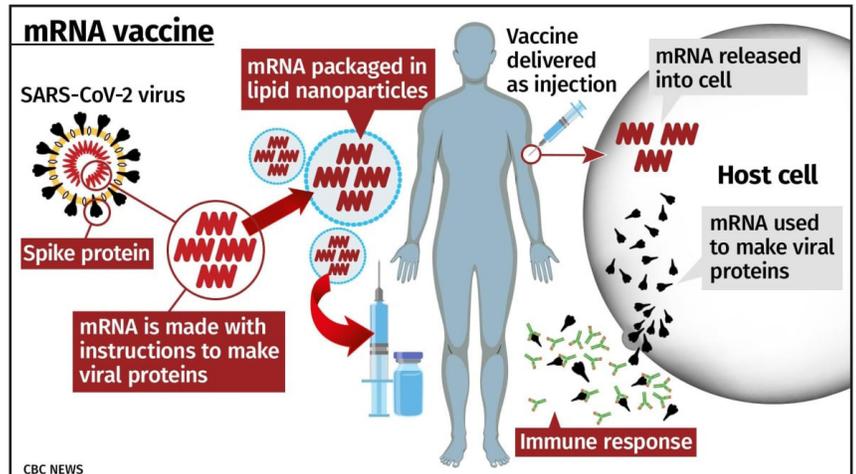
HOW DO THE VACCINES WORK?

Vaccines stimulate and train a person's immune system to fight the infection vaccinated against (in this case COVID-19) so that the person either does not develop the disease or has only mild disease. Vaccines often (but not always) provide long-lasting immunity to disease without the risk of serious illness.

In the case of COVID-19, there are many vaccines in development. There are 3 vaccines that will be ready for emergency approval by the Food and Drug Administration (FDA). Two vaccines are mRNA vaccines (Pfizer and Moderna) and one vaccine (AstraZeneca) is a viral vector DNA vaccine.

- **mRNA Vaccines:**

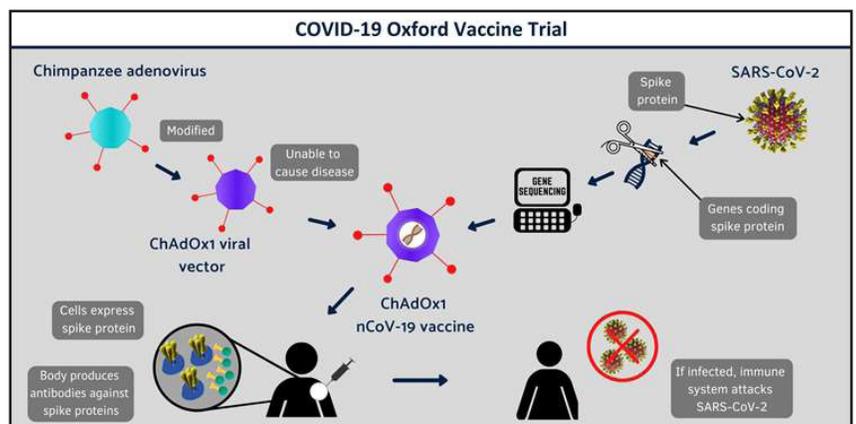
mRNA is the specific instruction template for making a specific protein created from the DNA instructions found on our chromosomes in the nucleus of our cells. Once created, the mRNA is transported to the ribosomes, the protein-manufacturing site in our cells. The specific mRNA provides the instructions for the ribosome to make a specific protein. In the case of COVID-19, the Pfizer and Moderna vaccines utilize mRNA instructions for the COVID-19 spike protein packaged in lipid nanoparticles. Once injected, the mRNA is taken up by cells in our body and these cells then make the COVID-19 spike protein. The spike protein provokes an immune response (specific antibodies and other responses) which stimulates and trains our immune system to fight the COVID-19 virus.



After approximately 4 weeks, if a vaccinated person is infected with the COVID-19 virus, their immune system quickly reacts and neutralizes the virus resulting in brief minimal or mild disease.

- **Viral Vector DNA Vaccines:**

Viral vector vaccines work by using a very weak virus as the package for delivering a small piece of DNA that codes to make a specific protein when present in the body causes an immune response. In the case of the AstraZeneca vaccine, the virus vector is harmless chimpanzee adenovirus called ChAdOx1 and the small piece of DNA codes for the COVID-19 spike protein. Once injected, the spike virus DNA is taken up by cells in our body and these cells then make COVID-19 spike protein. The spike protein provokes an immune response (specific antibodies and other responses) which stimulates and trains our immune system to fight the COVID-19 virus.



After approximately 4 weeks, if a vaccinated person is infected with the COVID-19 virus, their immune system quickly reacts and neutralizes the virus resulting in brief minimal or mild disease.

ARE THEY SAFE?

Initial data from Pfizer and Moderna mRNA vaccine trials showed no serious adverse side effects. Mild-to-moderate pain at the injection site, fatigue, chills, headache and muscle aches were common. Fever was infrequent. Side effects were more common after the second dose of the vaccine.

Initial data from the AstraZeneca viral vector DNA vaccine trial showed no serious side effects. Mild-to-moderate pain at the injection site, fatigue, chills, headache, muscle aches and fever were common.

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Questions About COVID-19 Vaccine

CONTINUED

ANY PRECAUTIONS OR CONTRAINDICATIONS?

At this time there are no specific contraindications and nothing special related to CF patients.

ANY BRAND PREFERENCES?

Which vaccines will be utilized depends upon which ones receive FDA emergency approval, how fast they can be produced and how easily they can be delivered. The two mRNA vaccines will most likely be approved first. Both require extremely cold storage, although the Moderna vaccine is stable for longer and can be kept in a regular refrigerator for up to 30 days without losing potency. Thus the brand you receive will probably depend upon what is available in your community and if you are in a prioritized population. Priorities will be recommended by the Centers for Disease Control, but ultimately will be decided by each state. Since CF is a chronic lung disease and thus a risk factor for more severe COVID-19 disease, it will most likely receive a higher priority than young healthy persons.

WHAT DO WE NOT KNOW?

We don't know how long immunity from the vaccines will last and if vaccination will be required every year like the flu shot. We also do not know about very rare side effects. However, the benefits of the vaccines will far, far, far outweigh the very small risk of very rare side effects.

Your Atrium Health CF Care Center is available to answer questions and provide more information as more becomes known about each vaccine. It is an amazing achievement by many individual researchers and labs to have several COVID-19 vaccines becoming available in less than one year from the start of the pandemic. However, the pandemic is not over. We must continue to practice wearing masks, keeping physically distant, avoiding groups of more than 10 persons, not participating in indoor events, and frequently practicing hand hygiene. These are our best defenses until most people are vaccinated.

Members Wanted

JOIN THE FAMILY ADVISORY BOARD

The Charlotte CF Family Advisory Board is looking for new members! We meet monthly to discuss current initiatives with the Atrium Health CF Care Team, as well as work on special projects to improve the experience of local CF families while in clinic, during hospital visits, and while navigating daily life. All meetings are currently virtual. We would like to add a few parents/caregivers and also expand to include adult CF patients to our advisory board.

If you would like to join the FAB or want more information about the position, please email charlotteCFfamilies@gmail.com.

Visit our website charlotteCFfamilies.org for additional resources and information about the FAB. Follow on social for updates & event reminders.

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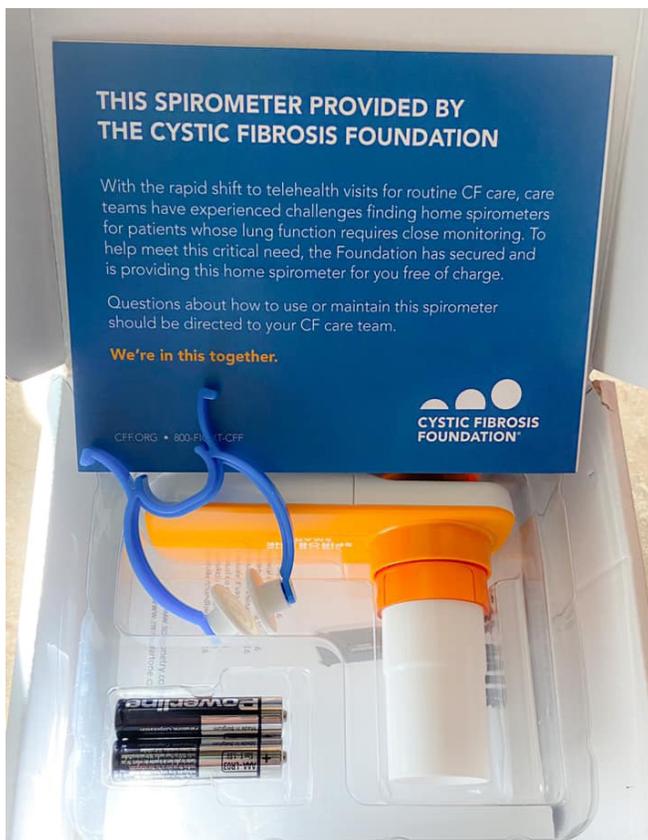
2020 CF Education Day Recap

Thanks to everyone who attended our annual CF Education Day on Saturday, November 7th. If you missed this year's event, we compiled recordings and slides from each of our presenters, including our CF panel! **You can watch the sessions online at: charlottectffamilies.org/edu-recap**

Thank You to our Sponsors!



Have You Used Your Home Spirometer?



The Cystic Fibrosis Foundation has arranged for over 10,000 home spirometers to be provided to care centers to support continued access to high quality, comprehensive care during the COVID-19 pandemic.

The “ZEPHYRx Breathe Easy” app connects your phone or tablet to the home spirometer, allowing patients to take a Pulmonary Function Test (PFT) from home or in clinic and share the results with your CF Care Team.

We are finalizing easy-to-follow instructions on how to set-up the device and properly take a test using the home device & the ZEPHYRx app, and automatically share your results with the CF Care Team at Levine Children's Specialty Center. Instructions will be shared as soon as available.

In the meantime, you can watch the ZEPHYRx video at charlotteCFfamilies.org/virtual-care.

If you have questions or need assistance setting up your device, contact your Atrium Health CF Respiratory Team (Eileen or Torina) at 704-355-2379.

34th Annual NACFC Went Virtual

The 2020 North American Cystic Fibrosis Conference (NACFC) went virtual this year, but our Care Team still had access to the same great content. During our annual CF Education Day (also virtual!), Dr. Schellhase shared highlights from the conference, including the latest CF research and advances in CF therapies.



The NACFC livestream archives are now available on the CFF YouTube page. You can browse the playlist of educational presentations, including: plenaries, discipline groups, workshops, and symposium sessions on topics ranging from lessons learned from the COVID-19 pandemic, cystic fibrosis-related diabetes, CFTR modulators, and more.

We've also recorded the presentation from our CF Education Day, if you'd like to hear how these CF advancements apply to our local CF community. Watch online at: charlotteCFfamilies.org/updates/atrium-health-cf-update-dr-schellhase

CF Care Team Spotlight

ANDREA WESTMORELAND



Andrea Westmoreland is a Certified Child Life Specialist at Levine Children's Hospital. For the past 17 years, she has worked on several inpatient units supporting a wide variety of patients in learning about the hospital, preparing for procedures, and understanding their diagnosis and treatment plans. Over time, Andrea developed a passion for supporting patients with Cystic Fibrosis and has focused much of time on improving the hospital experience for patients with CF and their families. In addition, Andrea has worked with both the pediatric and adult CF teams to support patients' transitions from pediatric to adult care. Outside of the hospital, Andrea enjoys spending time with her family, which includes her husband, two daughters, and two Great Danes, traveling to the beach and mountains, playing games, and reading.

Certified Child Life Specialists (CCLSs) are educated in child development and trained to apply that knowledge to help reduce negative impacts of illness and injury. CCLSs work with families and the healthcare team to support the psychosocial, emotional, and developmental needs of children and adolescents by offering therapeutic play, preparation for procedures, and developmentally appropriate education. The goal of child life is to reduce the anxiety, fear, and pain that can be associated with hospitalization and illness, whether short term or chronic, to improve healthcare experiences and outcomes for patients and their families.

Creating a Comfortable Hospital Experience



When a child with CF is admitted to the hospital, most often their stay is 2 weeks or more. CF patients are always on contact precautions and time out of their room is limited. It is important for patients to have a choice in what helps him/her cope with extended hospitalization.

The child and/or guardian will fill out a "get to know me" form including questions about the child's favorite games, crafts, animal, color, etc. With the information received from this form, the Child Life Specialist will create a "Pick Me Up basket" for these patients to have during their extended hospitalization. The purpose of the baskets is to bring joy, avoid boredom, increase comfort, and engage the child/family with the care team.

A generous grant was provided by the Lyon Child Life Endowment to fund this project.

Newborn Kits



Hello! My name is Danielle and my husband Daniel and I have an (almost) two year old son, Cameron, who has cystic fibrosis. When Daniel and I found out about Cameron's CF diagnoses we were obviously devastated and shocked. As we started on the journey, we discovered items that made our lives easier while also learning tips from other CF families. Treating a newborn child with CF is extremely challenging and can also feel isolating. When we joined the Family Advisory Board, we learned about a project to develop a box of items for newly diagnosed infants. Daniel and I both felt that we would be a perfect fit to partner in and help to get the boxes started. The items we came up with were ones that we thought would help make other parents lives just a little bit easier in one of the hardest times. Our goal is that these boxes will not only be helpful but also be a way that families know that they have support.

Below are the items included in the newborn kits:

- **Applesauce pouches and spoons:**
These pouches are very easy to use especially when on the go. The spoons attach right to the pouches. They are designed so the spoon never touches any surface. They also have a cap for storage in between doses.
- **Tupperware:**
It's hard to keep track of how many enzymes an infant can have per day. This is a great tool to help stay organized.
- **Contact case:**
These contact cases allow a parent to predose 1/2 doses or have a whole dose already opened and ready to sprinkle on the applesauce!
- **Fridababy Paci:**
Trying to give a newborn the orange vitamins in a syringe is tricky! The Paci has a syringe that attaches to it. The vitamins can be administered through the Paci and bypasses the taste buds. Game changer!
- **Burp cloth:**
Those orange vitamins stain EVERYTHING. The burp cloth is helpful to catch any spit up.
- **Storage bucket:**
Staying organized is a huge part of being a CF parent. The bucket can be used to help store any medications or supplies.



This holiday season do what's best for you and your loved ones

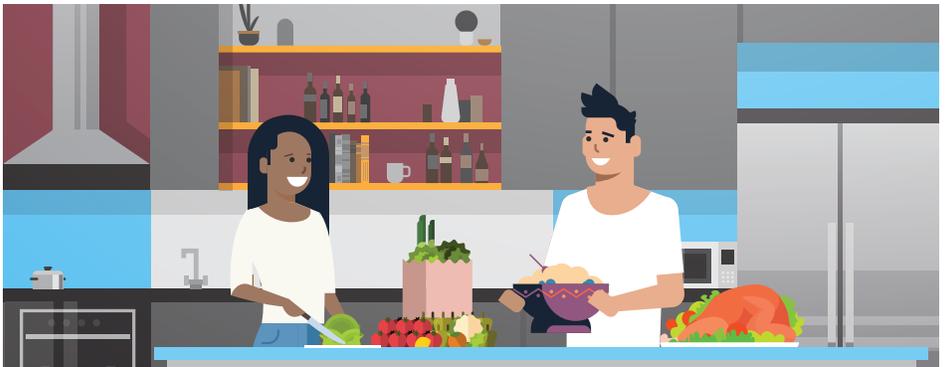
Being away from family and friends during the holidays can be hard.



Hard choices to be apart this year may mean that you can spend many more years with your loved ones.



When you talk with your friends and family about plans, it's ok if you decide to stay home and remain apart from others.



Do what is best for your health and the health of your loved ones. This year spend time with those in your own household.



Doing what's best for you includes eating healthy foods and getting enough sleep.



Make time to take care of your body and stay active to lessen fatigue, anxiety, and sadness.



Substance Abuse and Mental Health Services Administration
Disaster Distress Hotline: 1-800-985-5990 or text TalkWithUs to 66746

cdc.gov/coronavirus