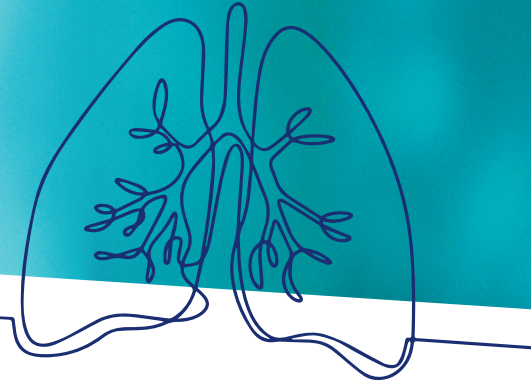


# CYSTIC FIBROSIS

## Patient & Family Advisory Council

DHMC CF Center



**April Issue  
2022**

The DHMC CF Patient and Family Advisory Council is a group of patients and families who live with cystic fibrosis, and members of the CF care team. We meet virtually every two months, and collaborate on projects that will enhance CF care.

## Our Mission

The DHMC CF Patient and Family Advisory Council seeks to enhance the care and quality of life of the CF population. The CF PFAC works in partnership with the CF Care Center to advocate on behalf of parents/caregivers and patients for the best quality of care.

Please email us at [nhcfpatientfam@gmail.com](mailto:nhcfpatientfam@gmail.com) if you are interested in being part of this group.

Newsletter team: Emily K. Dutille, Roni I. Finkelstein, Paula Garvey, Rosie Garvey, Kristin McCarthy, Ashlee Robinson, Jennifer Stover and Sarah Vooris,

## What's inside? Transition Edition

CF Community News

GI System Education Kits

Words of Wisdom: Transitions

Kids Can Cook!

Upcoming Fundraisers

and much more



Follow  
Us



# CF Community News



We will miss you but wish you the best on your retirement!

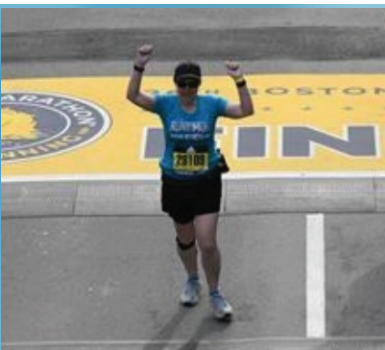
Congratulations to **Nicole Czyzycki, RN, MSN** for completing your Masters in Nursing Degree!

We are so lucky to have you on our Team!



## Are you an Organ Donor?

There are over 100,000 people in the US waiting for an organ donation. One organ donor can save up to 8 lives. Register today: [donatelife.net/register](http://donatelife.net/register)



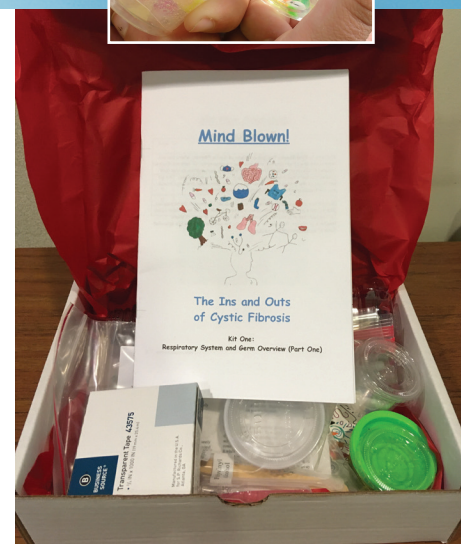
Congrats to the AMAZING Kerri for running the Boston Marathon! Kerri was diagnosed with CF when she was 5 and is now a healthy adult living with CF! Well done!

## Mind Blown Educational Kits!

The Boomer Esiason Foundation has accepted our funding proposal for future "MindBlown! The Ins and Outs of CF activity Kits"!

With their help, we will continue to make kits to help kids six and up learn and understand the various pieces of CF. Take a quick survey on the kits if you've completed them already: [surveymonkey.com/r/MKWD7RZ](http://surveymonkey.com/r/MKWD7RZ)

For more information about MindBlown kits contact Torie, Child Life Specialist. Congrats to CF mom Sarah and Torie on making this happen!



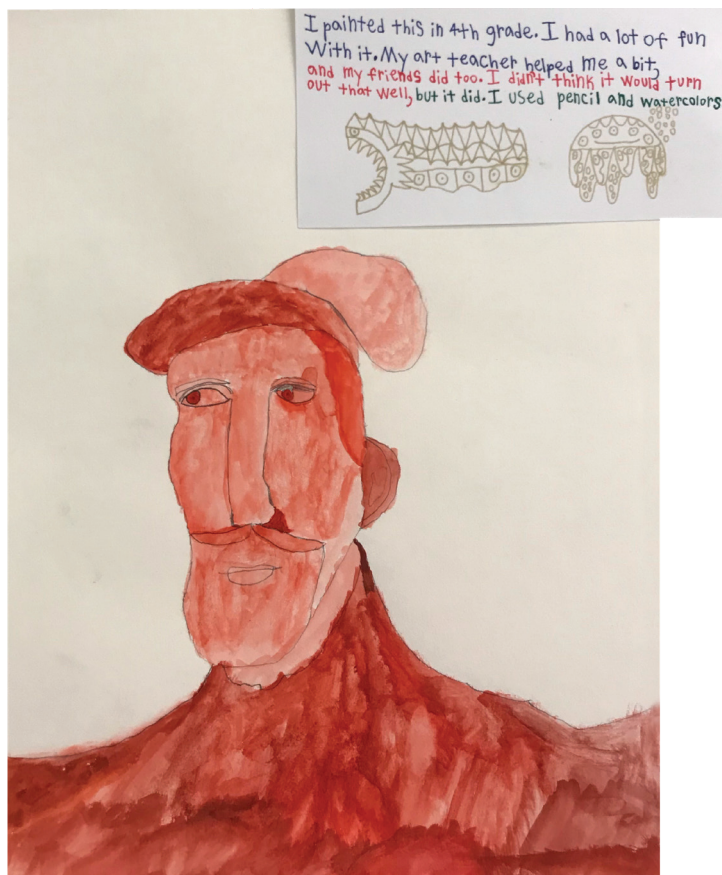


We are so excited that our CF art gallery is being displayed very soon.

Keep an eye on the website and social media for the virtual Art Gallery, meanwhile, here is a quick preview for you to enjoy!



*Becoming Mother* by Mother of patient Melody



by pedi patient Yves  
*Instead of titling it, he wrote a little paragraph about it which is included in this picture.*

# It takes Guts!

## GI System CF Education Kits Coming Soon

by Sarah Vooris

*MindBlown: The Ins and Outs of Cystic Fibrosis* are educational kits designed for learning about CF. MindBlown kits provide a fun and engaging way to explore how cystic fibrosis affects the body and how treatments help people with CF stay as healthy as possible. Each kit involves hands-on activities to teach about a specific body system so kids (and adults!) can learn about how the body works. Thank you to the Boomer Esiason Foundation who supplied additional funding to assist in the development of the GI kits.

MindBlown kits three and four focus on the *gastrointestinal (GI) system*. These two GI kits aim to help

you learn about how your body gets what it needs from food in order to thrive. You will also learn how CF changes how your body interacts with food and the treatments that help your body get the most from the fuel you provide. What's going on with the food and medicine inside your body? Get ready to explore concepts through activities like building a GI system model, making "poop," and more.

Each kit has all the supplies needed to make the accompanying set of projects. Some supplies (like scissors or tape) are meant to be used for multiple kits and were supplied with Kit #1 (respiratory system). If you have any questions or want to share feedback or photos, please reach out to the Lebanon CF child life specialist Torie at [victoria.miele@hitchcock.org](mailto:victoria.miele@hitchcock.org).

**Done with kits 1.1 and 1.2 on the respiratory system?**

Ask Torie in Lebanon or Sonya in Manchester for kit 2.1 and start your GI system exploration!





## How was your clinic visit?

After a clinic visit, in-person or virtually, you will be invited to share your feedback in the **Experience of Care survey**.



Designed for you and your family to **easily provide feedback** on the quality of care you experienced



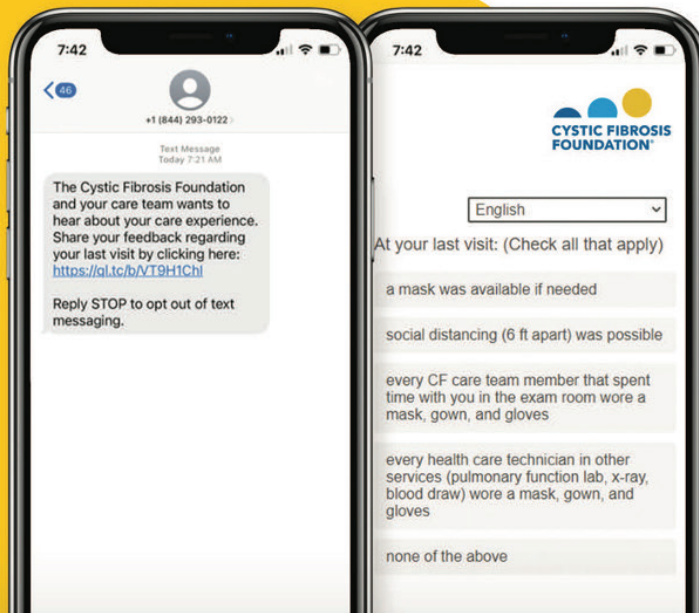
Expect a survey **invite via text or email**



Your **responses will be anonymous** and will not be linked to you or your child

**Together,  
Let's Make  
It Better**

Questions? Ask your  
CF Care Team.



# Roni's Corner

## Strengthening Our "Transition Muscles"

As a yoga teacher I often emphasize the importance of transitioning between postures during class. It takes a great deal of focus and mental flexibility to move the body from posture to posture, especially when encountering new sequences or poses. During these moments of transition, practitioners are, sometimes unknowingly, using tiny little stabilizer muscles in their ankles and wrists to remain steady. They are also creating new neural pathways and experiencing novel sensations throughout their bodies. These "transition" muscles don't get a lot of use in everyday life, and they are also located near two of the body's most vulnerable joints.

You've probably caught on by now, but I'm writing about yoga transitions as a metaphor for bigger life transitions. Transitional periods—like moving from preschool to kindergarten, or from pediatric care to adult care—can uncover our physical and emotional vulnerabilities by taking us out of our element. We get comfortable during periods of stability, then, all of a sudden, we need to engage our emotional "transition muscles" during times when we feel the most vulnerable.

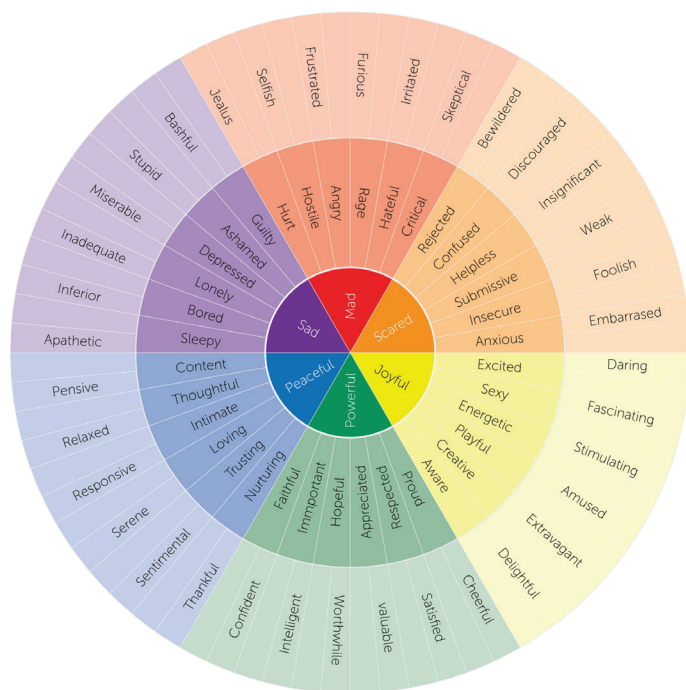
It may be helpful to prepare for these bigger transitions by flexing our "transition muscles" regularly—even during periods when things feel relatively stable. Here are some ideas:

**1. Name your feelings before bed every night:** by developing a daily awareness of how you feel during periods of stability, you may be more attuned to your emotions in times of transition. I suggest using a feelings wheel at first in order to expand your emotional vocabulary:

**2. Identify ways in which you are already emotionally flexible:** For example, do you enjoy trying new foods? Is it alright with you if your plans need to change at the last minute?

**3. Identify ways in which you are emotionally inflexible:** Do you get heated when someone parks in the spot you always park in? Are you rigid about your daily schedule?

**4. Change up your routine:** After identifying strengths and weaknesses in your emotional flexibility, challenge yourself by changing things up. Maybe you park in a new spot, or try a new lunch spot. Flexing your "transition muscles" in these small ways may bolster your coping skills in preparation for bigger transitions.



I am more than happy to discuss individual ways you may strengthen your emotional stability over time. Don't hesitate to ask me about it during your clinic visit, message me via MyDH, or call me at 603-650-5202. Happy transitioning!

# Words of Wisdom

## Working my Parents Out of a Job

How I'm taking over more of my CF care

By R. Vooris (7th grade)

I have begun managing more of my CF care. Over time, I've gradually learned what to do for my health and why. Some of the things I currently do include:

Keeping track of taking my pills, like when I take my modulator or when and how many enzymes to have with food

Cleaning and sterilizing the nebulizers

Switching from my nebulizers to my vest when it's time (without my parents reminding me over and over)

Going through my medication list with my providers during clinic visits

Calling the pharmacy for medication refills (with a parent)

One other major thing I did recently was spend part of my clinic visit with members of the team by myself. The clinic visit was organized in such a way that I was able to meet with the team together with my parents before having the independent part of the appointment. I wasn't concerned because my parents have always encouraged me to be more independent with taking care of myself. I knew what to say for the most part because I answered questions during appointments in the past. I normally speak for myself during clinic visits. I wasn't nervous.

When the portion I did alone was done, I was back with my parents who were part of any decisions about my care. Even though I had time alone with team members I knew I had the support of my parents and did not have to make decisions by myself. I had the solo time to take another step in learning about how to manage my own health.

# Transition Tips from a child life specialist

## Moving from pedi to adult clinic

**Practice makes perfect!** Prior to moving to adult land, try requesting your refills for prescriptions, use myDH to message your provider with a question, and make your clinic appointments yourself. Doing this while you are still with your familiar team can make you feel more comfortable. Are you extra nervous and feel like a tour of the space will help? No problem! That's something your CF team can easily set up.

**Learn about Insurance** Health insurance can be tough to understand. Take some time to figure out things like what a deductible means, where your coverage is, and prescription costs. Try chatting with your social worker who can help you iron these details out.

**Ask for help** Remember, just because you are in adult medicine doesn't mean you can't ask for support. We encourage you to continue to use your caregivers and medical staff as someone to lean on when times are tough. No question is too silly. We don't expect you to know it all or do it all yourself. That's why we are called your treatment TEAM!

# Transition Tips from a mom of a high school student

**Independence is a good thing:** As parents we need to encourage our children to be in control of their illness. Our job is to build their confidence in the early years by slowly shifting responsibilities over to them. By doing this they can become familiar with the necessary steps needed to maintain their health. The goal for our family was that by high school our daughter was able to handle all aspects of her treatments, monitor her medication and keep track of any new symptoms to report to her CF team.

**Communication is key:** One of the hardest things for me is knowing at some point I will not be going to clinic appointments anymore. Thankfully our children know their health better than anyone, and we need to trust they will communicate any concerns to their doctor without us in the room. In preparation for this, I have started waiting in the waiting room for the first few minutes of clinic, so my daughter can get comfortable with this next step. It may be helpful to prepare a list of questions with your child ahead of time for them to talk about.

**You can still be involved:** Your child may still need some help with the more complicated aspects of their care, and certainly when they feel overwhelmed. Lots of high school students have jobs, play a sport and face a heavy load of school work. You may help them out occasionally by preparing treatments, picking up their medications or simply ask how you can help..

**Letting go is hard:** As parents we've played a major role in managing the health of our children. Taking a step back from this is really scary. Our children need to know we will continue to be there to love and support them however we can. It may not be in the way of sterilizing nebulizers any longer, but could be volunteering at the CF Foundation or advocating for them in other ways.



## Transition Tips from your CF Team & PFAC members!

**Lynn, CF nurse**

“One tip—as I venture into a huge change in my life: Be Open to Change! ;-)”

**Nicole, CF nurse**

“Transitions can be stressful. Make a plan and be prepared, but be flexible and open when your plan veers off course. Use your voice. Ask questions and share your thoughts and needs. You are the best advocate for your health and your life.”

**Paula, mom of adult with CF**

“When you or your child is deciding on a college, check out and connect with Student Accessibility Services first, also investigate whether the college offers tuition insurance.”

**Rosie, adult with CF**

“When first entering the work-force, be as open as you are comfortable with about your health. It is good to explain that your health comes first and that there are a lot of things out of your control that healthy people may not understand. You might need to be flexible in job choices. Don't be too hard on yourself.”

**Kristin, mom of young child with CF**

“My advice would be to trust your child. They know what the norm is and can assume a certain amount of responsibility and advocate for themselves, even at a fairly young age. I remember being so worried about enzyme dosing when kindergarten started, but my daughter had no trouble reminding teachers and telling nurses exactly how things should go. Another bit of advice would be to try not to assume the worst. I was worried she would feel singled out having to visit the nurse every day. In reality, she loves her school nurses and can't wait to visit them at lunch.”

**Tracy, mom of adult with CF**

“Patience and understanding for your kids. Especially that our kids are considered adults at 18, when we keep them on insurance until they are 26.”

**Jack, adult with CF**

“Transitioning is a skill like any other and it's all about having a plan in place before you start. Before I was introduced to any of my professors, I met my new physician so that I would feel comfortable receiving care in a different setting. Now preparing to finish my undergraduate and pursue a master's degree, I'm glad that I got the chance to practice so that I can be better prepared for the future.”



# Kids can Cook!

## Encouraging Independence in the Kitchen!

By Paula Garvey, mom of an Adult with CF and Culinary teacher

Life is busy and parents of children with CF face extra challenges when planning meals and snacks, we wonder if our children are getting enough calories, is the food healthy, how many enzymes do they need? However, when kids can be part of the cooking process meal time can be easier. When they participate in the process of cooking they gain independence, and this independence leads to smoother transitions in other life experiences. Here are some tips I would like to share.



- Encourage participation from a young age, ask children to measure ingredients (helps with math skills too!). Mixing is a simple task. Peeling fruit!
- Ask children to make choices—red pepper or yellow pepper, they then feel more control over their food choices.
- Sneak in vegetables when you can—peppers on frozen pizza or in an omelet, grated carrots in Spaghetti sauce, grated zucchini in muffins.
- Eggs are a great source of protein and so simple and versatile to use. Mixing an omelet is a simple task that a young cook can master! Home made waffles and pancakes are simple for kids to mix ( don't forget to freeze any leftovers!)
- Avoid sugary snacks. Fruit is fantastic! Peanut butter is high in calories, fat, and protein—serve with carrot sticks or ask your child to slice an apple.
- Make healthy choices. Use vegetable oils rather than butter. Bake rather than fry, I LOVE my air fryer! Whole grains are so much better for us and help move food through the digestive tract and reduce the risk of constipation.
- Eat the rainbow—add color and make cooking fun! Garnish with fruit and berries, make smiley faces! Add peppers, carrots and corn to dishes. Even add food color to mashed potatoes if that will encourage eating!
- Try to stay healthy, when possible, we can add calories and still avoid unhealthy choices. Try to choose the least processed food that fit your budget. Purchase whatever is in season. Purchase whole fruits and vegetables, they are cheaper, more nutritious, and better for the planet with less packaging. Ask your kids to help chop and peel them under supervision. Frozen vegetables are a good source of nutrition and very convenient.
- The kitchen can potentially be a dangerous place so always ensure that they are in a safe environment and are supervised when using tools and equipment.
- Lastly, enjoy making a mess, cooking should be fun, this will encourage a love of cooking and teach a valuable life skill and encourage independence.

There are lots of great Kid Friendly recipe websites out there, here are few of my favorite websites!

[foodnetwork.com/recipes/packages/recipes-for-kids/cooking-with-kids/recipes-kids-can-make](https://foodnetwork.com/recipes/packages/recipes-for-kids/cooking-with-kids/recipes-kids-can-make)

[chef4cf.com](https://chef4cf.com)

[mykidslickthebowl.com](https://mykidslickthebowl.com)

[myplate.gov/life-stages/kids](https://myplate.gov/life-stages/kids)

[cff.org/community-posts/2021-04/how-i-avoid-making-different-meals-each-our-family-members](https://cff.org/community-posts/2021-04/how-i-avoid-making-different-meals-each-our-family-members)

# News From the Cystic Fibrosis Foundation

Upcoming Fundraisers



**GREAT STRIDES<sup>®</sup>**  
CYSTIC FIBROSIS FOUNDATION

**MAY**  
**14 & 15 2022**

**AUGUSTA, BANGOR, HANOVER,  
LANCASTER, NASHUA,  
PORTLAND, RUTLAND, SEABROOK,  
WOLFEBORO, YORK**

Visit [greatstrides.cff.org](http://greatstrides.cff.org)



## CF CYCLE FOR LIFE

CYSTIC FIBROSIS FOUNDATION

### July 16, 2022

Join us as we ride through some of the most picturesque and scenic terrain along the coasts of Maine and New Hampshire. CF Cycle for Life is a fully-supported ride with route options of 30 miles, 65 miles or a Century. From breakfast to our post cycle lunch party, you can enjoy fully stocked rest stops, bike mechanics for bicycle maintenance and repair and plenty of support vehicles to help you complete the ride. This unique event empowers participants to take action and demonstrate their fight in finding a cure for cystic fibrosis in a tangible, emotional and powerful way.



Cystic Fibrosis Foundation  
Northern New England Chapter  
20 Trafalgar Square, Suite 447  
Nashua, NH 03063

[Click for details](#)

# March on the Hill 2022

## CF Advocacy Update

by Sarah Vooris

*March on the Hill* is the Cystic Fibrosis Foundation's annual advocacy event, where volunteers from across the country meet with their members of Congress to advocate on behalf of their loved one(s) with CF. As a mother of an adolescent and teenager with CF, I was honored to represent those from VT and NH along with Josh Corringham, a sibling of someone with cystic fibrosis. Due to the ongoing COVID-19 pandemic, March on the Hill 2022 took place as a fully virtual event on March 17th, allowing numerous people with cystic fibrosis to advocate as well. We met via video conference with the offices of VT and NH members of Congress to discuss concerns about antimicrobial resistance and advocate for the PASTEUR Act.

### **Background: Antimicrobial Resistance and the Need for New Treatments**

The nature of the mucus in the lungs of people with cystic fibrosis makes this organ an ideal place for bacteria and other harmful pathogens to settle and multiply. As a result, people with CF are prone to long-lasting lung infections that deplete lung function and which may ultimately lead to the need for lung transplant or death. These lung infections are treated with antibiotics. Many people with CF battle difficult to treat infections for which few or no effective antibiotics are available. The threat of acquiring a pathogen that has no antibiotic to treat it, or for an individual to develop resistance over time rendering available antibiotics useless, is real and stressful.

Incredible progress has been made in the care of people with CF. For example, many in the CF community benefit from highly effective modulators that treat the underlying cause of cystic fibrosis. These have been absolutely life changing. But this position is a tenuous one. Despite modulators, many still have colonizations of pathogens that cause infection. There are also numerous individuals with CF not eligible for modulators or who can not take them. With no control or cure yet for all with CF the risk of infection remains, infections that could instantly undermine the major wins made by individuals with cystic fibrosis. The CF community is a cautioning example of what is and can happen with the lack of antibiotic options and risk of antimicrobial resistance (AMR) for anyone.

Today the pipeline of antibiotics in development is not adequate to address current or future needs. The system has not evolved along with the needs of the CF community and that of the general population. The longer we go without a comprehensive solution to address antibiotic development, the more the pipeline will degrade, further limiting options for people with CF and others in need of

successful treatments. The CF Foundation recognizes the seriousness of this problem and has already dedicated over \$109 million dollars to address the chronic infections common with cystic fibrosis. However, more needs to be done. It is necessary to enlist the help of Congress, with legislation part of the solution.

## **PASTEUR Act**

During March on the Hill, Senators and members of the House of Representatives were asked to lend their support to the PASTEUR Act by cosponsoring the legislation. The PASTEUR Act (H.R. 3932 / S. 2076), is a bipartisan, bicameral bill that aims to support the development of new antibiotics for people with cystic fibrosis and others affected by antimicrobial resistance. The Act establishes a contract model for qualifying medicines, with a payment structure based on value not on sales volume set up to fund companies that created the chosen successful medicines (FDA approved antibiotics). This change in focus would help sustain current options by encouraging good stewardship. It would also spur the development of new antibiotics.

## **Add Your Voice**

Just like I did, you can help as a constituent in your Congressional district by asking your representatives to cosponsor the PASTEUR Act. No matter your connection to CF, you have a unique and valuable perspective from experiences with infections, antibiotics, how the risk of infection changes how you live each day, what it's like to wait on culture results, and more - insight that supports the necessity of the PASTEUR Act and the changes it could render.

You don't have to meet directly with your Congressional officials as I did, but can still add your voice. The CF Foundation makes it easy to advocate. The link below leads you to an automatic email process with which you can communicate with your Senate and House of Representatives officials. Many staff members we met with during March on the Hill indicated that they have been hearing about the Act from constituents. Your voice matters.

### **Ask Your Members of Congress to Cosponsor the PASTEUR Act**



[act.cff.org/5h8P1NZ](http://act.cff.org/5h8P1NZ)

## **Questions?**

Want to know how you can get more involved with advocacy?

Have questions about the PASTEUR Act and what's happening in your state with this legislation?

If so, please email: [nhcfpatientfam@gmail.com](mailto:nhcfpatientfam@gmail.com)