



Keeping healthy and happy this Holiday Season

It's that time of year again when cold and flu season coincides with holiday gatherings, parties, and celebrations. Each year the question comes up as to how to keep kids with CF healthy and still enjoy the holidays. The answer is different for every family and every situation. Additionally, family and friends have varying levels of understanding and empathy. With some CF kids, it is hard for others to accept how sick they could be, when they don't look sick.

TACTICS FOR THE HOLIDAY SEASON

Here are several tactics that can be used to keep your child with CF healthy while still enjoying the many gatherings during the holiday season:

- Before the gathering, ask everyone on the invite list if they are sick. If you don't know everyone who is attending, reach out to the host and ask them to check in with the others.
- Ask the host to let you know if someone has arrived at the gathering who is sick.
- Don't attend the event if someone is sick and insists on coming anyway.
 - It isn't always practical to ask someone sick to leave a family party when they've flown in from across the country or you have done the same. In those situations, a few other options are:
 - ❖ Ask that everyone frequently wash their hands
 - ❖ Ask the ill individual to keep at least six feet away from the child with CF.
 - ❖ Consider face-timing or skyping in to the party.
 - ❖ Consider having the ill individual come early, while the family with CF comes to the party later – with no overlap in attendance
- In lieu of attending the event, do something special in place of the party.

While some of these tactics may be difficult to actually implement, it is certainly worth the effort to avoid an exacerbation, a round of antibiotics, or worse yet, a hospital stay. As parents, you are the best advocates for your children's health, so don't hesitate to do what you feel is in the best interest of your child, and family.

When it comes down to it, it is basically a risk-benefit analysis. Each child will have varying degrees of interest in the gathering, each child will have different health concerns, and each family will choose to address things uniquely. It can be a very difficult, emotional decision for anyone to miss an important holiday event. For young kids, be sure to set proper expectations about the possibility of leaving early or changing plans. Older kids can help list out pros and cons and be part of the decision-making process of how to stay healthy.

Additionally, be certain to maintain your normal health management routine during the holiday season. Although maintaining a routine is more difficult to do during the holiday season, it is important to help keep your child healthy as they are exposed to more germs during this season.

Pay special attention to:

- Getting enough sleep
- Maintaining proper nutrition & regular exercise
- Continue with normal treatment regimen

Be conscious, considerate, and pro-active during the holiday season to keep your child with CF healthy. But, be sure to not let worry and concern take away from the fun of the season! Happy Holidays!

The CF Breeze will be distributed electronically for patients and families of Children's Hospital and CRCCS.

To be added to the distribution list or to update your e-mail address, please complete a listserv form available in the lobby of CRCCS or by contacting Mary Sachs or Sandy Landvik.



An Interview with a Sibling

by Amy Schwanz



Earlier tonight I asked my 14-year old daughter, Brynn to write a short article (only two paragraphs, I clarified) about having a younger sister with CF. For any of you that have a teenager in your home, you won't likely be surprised to hear that my sweet angelic teenager was not anxious or even willing to write about this topic (or any topic, for that matter) that did not come as a requirement from a teacher!

My next approach was to have Brynn answer some questions about how her life is impacted by her younger sister, Kyra having CF, and I would write it. Brynn was more receptive to this idea because it required less work on her part, but I would certainly not say she was an engaged or willing participant! So, here's how that conversation went....

Me: How is our family different from other families because Kyra has CF?

Brynn: I don't know.

Me: Seriously, you can't think of anything?

Brynn: How would I know what another family is like? I only know our family... with Kyra and CF. I have never had a different family.

I thought, 'okay... she got me on that one', but I wouldn't give up that easily...

Me: Anything else?

Brynn: Ok. Well, I think Kyra gets more attention than I do, but I think that's just because she is younger than me, and she's well... she's Kyra... not because she has CF.

Note: Kyra does have a tendency for the dramatic and Brynn is quite mellow.

Me: What are the downsides of having a sister with CF?

Brynn: I have to wash and sterilize the nebs, and no one likes doing that! I know it's worse for Kyra since she has to actually do the vest, but I REALLY do not like listening to the vest or listening to Kyra complain about it.

After hearing that response, my husband chimed in from the other room....

Mark: Are you kidding me? You honestly think that is the biggest problem? UGH!

Brynn: I do feel bad that Kyra has to do her vest and her nebs all the time because I know it takes a lot of time and it's not fun. Also, you guys are always worried about her meds coming in the mail on time.

Note: She didn't add that we are also worried about how we are going to pay for those meds (hopefully she hasn't picked up on that worry of ours yet).

Me: Anything else? Do you think we are more careful about germs and sickness than other people?

Brynn: I don't know. I'm a germ-a-phobe, you know that! But, I don't know if it's because Kyra has CF or if that's just the way I was born.

Me: What are the positives of having a sister with CF?

Brynn: I don't know.

Me: Really? Nothing? I can think of several. How about our Make-A-Wish trip to Hawaii?

Brynn: Oh yeah! That was awesome! Plus, we get tickets to fun stuff sometimes from HopeKids and Children's Hospital.

Like every mom, I worry about each of my children; I worry about a lot of things, a lot of time! I worry about how to keep them healthy – both physically and mentally! And, like many of you, I worry about how my child without CF feels and manages life with a sibling with CF. Based on this conversation (and previous conversations) with Brynn, and never witnessing any jealousy or anxiety related to Kyra, I think she must be doing okay in the mental health department.

Children's offers SibShops (612-813-7127) for the siblings of patients; consider looking into those programs for your children without CF. Brynn attended one of the SibShops years ago when she was around 8 years old; I will never forget Brynn's response when we were explaining to her what the SibShop event was (crafts, activities, pizza lunch). She said "What will Kyra eat for lunch if they are having pizza? She doesn't like pizza. We'll have to bring something that she likes." Brynn had no concept of going to this fun activity without her sister! After some convincing, she did go (albeit without Kyra) and had fun, but she decided that she would just rather play with Kyra than do it again. (BTW – that was before Brynn became a teenager who only wants to spend time with friends). I'm not telling you this to dissuade you from reaching out for these types of activities for your own children – only to let you know that our kids (all of our kids) – the ones with CF and the ones without CF – are resilient, tough, and amazing people – more so than we give them credit for!



Meet Our New Team Member

We would like to take this opportunity to introduce **Christine Benoit**, our Senior Clinical Research Coordinator on the CF Research Team. Over the course of the coming year, Christine will be working to increase outreach in the CF community and among our families to promote research and ensure that everyone knows about the exciting studies happening here at Children's, as well as at other centers in the region. Christine plans to pop into clinic visits from time to time to discuss research opportunities with families, so don't be surprised if you see her at your next visit!



Research Assistant, Sophie Shogren, will soon begin calling families about a vest therapy adherence study we are conducting in collaboration with Hill-Rom. If you are currently using a Hill-Rom vest and have been on vest therapy for over 1 year, you are eligible for this study! Sophie will be calling all eligible families in the coming months to provide more details.

Medical Research Updates

Studies Open for Enrollment

1. Saline Hypertonic In Preschoolers (SHIP-001): Patients with CF ages 36-72 months may be eligible. **Open for enrollment!**
2. VX14-809-109: A Phase 3, Double Blind, Placebo Controlled, Parallel Group Study to Evaluate the Efficacy and Safety of Lumacaftor in Combination With Ivacaftor in Subjects Aged 6 Through 11 Years With Cystic Fibrosis, Homozygous for the F508del CFTR Mutation Open for enrollment!
3. Vertex14-661-107: A Phase 3, Randomized, Double Blind, Placebo Controlled, Parallel Group Study to Evaluate the Efficacy and Safety of VX-661 in Combination With Ivacaftor in Subjects Aged 12 Years and Older With Cystic Fibrosis, Heterozygous for the F508del CFTR Mutation and With a Second CFTR Mutation That Is Not Likely to Respond to VX-661 and/or Ivacaftor Therapy Open for enrollment!
4. High-Frequency Chest Wall Oscillation Therapy Adherence: Utilization of Novel Data Reporting Technology to Measure Adherence among Children and Adolescents with Cystic Fibrosis Open for enrollment!



To learn more about the Cystic Fibrosis Research Program contact:
Mahrya Johnson at 612-813-6384 or via email at mahrya.johnson@childrensmn.org
Christine Benoit at 612-220-6254 or via email at christine.benoit@childrensmn.org



Meet our New CF Dietitian

I am so excited to be coming on board as the new dietitian for the cystic fibrosis community at Children's Minnesota. Although I am new to the CF group, I have been working at Children's MN for just over 2 years in the pediatric and cardiovascular intensive care units.

I was born and raised in the Twin Cities and attended the University of Minnesota to complete my undergraduate degree in nutrition and dietetics. During my time as a Dietetic Intern at the University of Minnesota Medical Center, Fairview, I discovered my passion for working with kids and am so grateful to have that opportunity here at Children's.

In my free time, some things I enjoy are yoga, walking and biking around the lakes or on the trails and enjoying time with family and friends. My favorite treats are freshly baked oatmeal chocolate chip cookies. I don't watch TV often but if I do it is more than likely going to be something on the Food Network.

I am really looking forward to getting to know all of you in the near future. Please know that I am here to answer any questions you have with regard to nutrition and am only a phone call or email away.

Warmest holiday wishes,

Kate Henschel, RD, LD



Medication 101

Prednisone

(corticosteroids, decadron, Solu- Medrol, Prednisolone)

Use/Action:

Mimic the effects of hormones your body naturally produces in your adrenal glands
Decrease inflammation
Can suppress immune system
Used to treat asthma and allergic bronchopulmonary aspergillosis (ABPA) and rejection in transplant patients

Dosage Form:

By mouth in pill or liquid form
By inhaler or nebulizer (flovent, budesonide, pulmicort, qvar)
By injection or IV

Side Effects:

(more common with injection or oral):

Stomach upset
Elevated glucose levels especially with CF related diabetes (CFRD)
Fluid retention
Increased appetite /weight gain
Behavior and mood effects

(More common with inhaled or nebulized):

Oral thrush
Hoarseness

Long term use side effects include:

Cataracts
May affect growth



Salted Caramel Peanut Butter Fudge

Adapted from Worth Whisking on yummys.com

Makes approximately 3 pounds or 48 - 1 ounce servings



Ingredients

Fudge

- 2 cups creamy peanut butter (not natural type)
- 2 cups (4 sticks) salted butter cut into ½ inch cubes
- 2 teaspoons vanilla extract
- 8 cups powdered sugar, sifted
- ¼ teaspoon sea salt

Caramel Filling

- 18 caramels (from 14 ounce bag, example Kraft or Brach's soft caramels), unwrapped
- 8 ounces sweetened condensed milk
- ⅛ cup creamy peanut butter (not natural type)
- ¼ cup honey roasted peanuts, chopped

Instructions

Fudge

1. Butter a 9x5 inch loaf pan. Line bottom and sides of pan with parchment paper long enough such that parchment paper overhangs each side of the pan. Butter parchment paper.
2. In a large saucepan over medium heat, heat the butter and the peanut butter until the mixture comes to a boil. Remove from heat.
3. Stir in the vanilla extract.
4. Add half of the powdered sugar and stir until combined. Add the remaining powdered sugar until smooth and no lumps remain.
5. Spread ⅔ of the fudge into the prepared pan. Set aside the remaining fudge.

Caramel Filling

1. In a medium saucepan, heat caramels and condensed milk over medium heat, stirring constantly, until caramels are melted.
2. Stir in the peanut butter and heat until the mixture comes to a boil. Cook 2 minutes, stirring almost constantly.
3. Remove from heat and stir in the chopped peanuts.

Final Assembly

1. Immediately spread caramel filling over fudge in pan. Quickly cover the caramel layer with remaining fudge and smooth with a spatula or the back of a spoon.
2. For extra sparkle, sprinkle a small amount of sea salt evenly across the top of the fudge. (optional)
3. Press a piece of plastic wrap directly on the fudge and refrigerate until firm, at least 3 hours.
4. To remove fudge from pan, run a thin knife, offset spatula, or similar between the parchment paper and the pan. Pull up on the parchment handles to lift fudge out of pan.

Nutrition information

Per 1 ounce serving (1/48 of batch): 250 calories, 14.8 g total fat, 126 mg sodium, 27.6 g total carbohydrate, 3.8 g protein