

# NEWSLETTER

## PARTNERS IN CARE FROM NACFC 2018

*By Lilly Mees, LMSW*

It was great to have our teams go to the North American Cystic Fibrosis Conference (NACFC) in October. We were able to learn a lot, along with over 5,000 clinicians, providers and caregivers. There were three plenary sessions that were live streamed and recorded. They can be viewed on YouTube at [www.youtube.com/playlist?list=PLhoQ6vyZhggpBW\\_BOAR3Dle6vesDNbniK](http://www.youtube.com/playlist?list=PLhoQ6vyZhggpBW_BOAR3Dle6vesDNbniK)

A highlight for me was the 3rd and last plenary session on the 5 Ways to Partner with your CF Care Team. You can utilize these tips to help prepare for your clinic visits:

**1) Be Open and Ask for Help With Your Care Plan** - Share openly and honestly about your care needs so your team

can work with you.

**2) Share What's Going on in Your Life** - When life changes, your care plan may need to change too.

**3) Communicate Outside of the Clinic** - You manage CF everyday, so why wait until clinic to ask questions?

**4) Invite Other People Into Your Care Planning** - Managing CF doesn't have to be a solo activity.

**5) Approach Difficult Conversations with Respect** - You and your care team are motivated by a shared goal: improving your health.

Please visit [cff.org/PartnersInCare](http://cff.org/PartnersInCare) for more information about Partnership for Sustaining Daily Care.

## NUTRITION PERSPECTIVES FROM NACFC 2018

*By Maria Plant, DCN, RN*

The North American Cystic Fibrosis Conference was an inspiring showcase of the latest research and clinical approaches for optimal care of individuals with CF. Regarding nutrition the focus continues to be on improving nutritional status with the goal of optimizing lung function and health.

Many interesting perspectives and studies were shared. Topics around nutrition ranged from nutrition-focused physical exam techniques to assessing food preparation skills. Two studies that I found particularly interesting and insightful which were eloquently presented are summarized below.

The first study explored the relationship between body composition and lung function. Currently achieving and maintain goal body mass index (BMI) is a primary focuses of nutritional care due to the positive associations with BMI and lung function in the CF population. However, BMI alone does not give us specific information on body composition such as lean body mass compared to fat mass or the distribution of fat tissue in the body. Loss of lean body mass has been negatively associated with lung function in patients with CF. In addition, we know that excess abdominal fat has negative health associations

for those without CF. In this small pilot study researchers found a positive correlation between lean body mass, BMI and lung function and an inverse association between fat mass and lung function. This study highlights the need for more specific body composition measurements to add to BMI as indicators of nutritional status, lung function and health outcomes.

Another study explored the relation between BMI and life skills. The Cystic Fibrosis Foundation has suggested BMI targets of 22 kg/m<sup>2</sup> for females with CF and 23 kg/m<sup>2</sup> for males with CF. These researchers explored whether life skills such as obtaining and preparing food had an impact on BMI. The researchers utilized a worksheet to survey participants' self-care skills which included a question regarding their grocery shopping and cooking habits. In this small study of 15 adults with CF, researchers found that those who answered "yes" regarding the ability to shop and cook for themselves had a higher mean BMI (21.4 kg/m<sup>2</sup>) compared to those who answered "no" (BMI 16.9 kg/m<sup>2</sup>). This study highlights the importance of interventions focusing on teaching skill such as these to support higher BMI.

I hope you find this information as interesting as I did. The conference was definitely inspiring and informative!



## FAMILY/CAREGIVER SUPPORT GROUP

We would love to see you at the CF Family/Caregiver Support Group one Monday a month at Playformance.

“As a parent of 1-year-old twins with Cystic Fibrosis, I felt very overwhelmed and isolated in the first few weeks after diagnosis. Going to the parent/caregiver support group was such a wonderful outlet for me to ask questions, feel no-judgement, to be listen to and to have fun all at the same time! We played a game and had such a yummy dinner! My Mom even went with me, and we felt so welcomed, I personally felt 100% better after going to group and meeting with families who are all going through this thing together! I appreciate the fun setting, and time we spend together just talking about life, other siblings without CF, work, and just about anything that is on our minds really! I would love to meet all of you, as I feel everyone has such great insights, tip and tricks, for newly diagnosed Moms like me!” - Amy

You can get more information at [www.facebook.com/groups/tucsoncffamilies](http://www.facebook.com/groups/tucsoncffamilies)

## WISHES ARE GOOD MEDICINE

The Arizona Make-A-Wish chapter wants to grant your child’s wish. Make-A-Wish is committed to creating life-changing wishes for children with critical illnesses. The psychological effect of a wish being granted to a child has a profound impact on not only their own physical and mental health, but the family’s as well. 97% of wish families observed improvement of their wish kids’ emotional health. 74% of wish parents observed the wish experience mark a turning point in their own children’s response to treatment. Wishes are good medicine for children and families.

**Who is eligible for a wish?** A child with a critical illness who has reached the age of 2½ and is younger than 18 at the time of referral is potentially eligible for a wish. All children with cystic fibrosis qualify for a wish. One wish per eligible child.

**What can a child wish for?** The child’s imagination is always the driving force in determining, designing and coordinating the wish experience. Wish requests typically fall into one of five categories, but every wish is unique and powerful.

If you are interested in having your child’s wish granted, please contact your social worker, Randee Luben, at [Randee@email.arizona.edu](mailto:Randee@email.arizona.edu) or (520)626-1569. For more information on Make-A-Wish, visit their website at [www.arizona.wish.org](http://www.arizona.wish.org).

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