

Report on my 2015 NACFC experience

by Chris Kvam

With the generous help of the CFFC, I was able to go to Phoenix, AZ for the 2015 North American CF Conference. I focused my time on the Social Work/Psych track of sessions, and tried to choose a mix of sessions I was already interested in, and things I didn't know much about. I did not attend any "science" or pharma related workshops, as I wasn't there for the biochem lesson, and I believe a lot of information about the CF drug pipeline and advancements are available elsewhere.

The highlight of my time at NACFC was the third plenary session – there is no health without mental health. I had participated in the International Mental Health Guidelines Committee, and had helped write the guidelines paper with the CFF mental health task force. Watching our work presented was incredible, and I believe that the message "There is no health without mental health" is an amazingly powerful one, and one that will transform CF care. It has been extensively documented that depression and anxiety negatively impacts adherence to treatment, quality of life, and health outcomes. The plenary included the announcement that the CFF would be funding grants to over 70 CF clinics in the US to implement the guidelines. I was on the grant awards committee, and am proud to say that the University of Rochester Adult program was funded. I am not certain whether or not the pediatric grant received funding. The integration of screening, prevention, and treatment for anxiety and depression represents a commitment to care for the whole person, not merely respiratory and digestive symptoms often associated with CF. It is my hope that this commitment to Mental Health care within the CF care environment leads to more meaningful care, increased adherence, and higher quality of life for all people with CF. The work continues with implementation and evaluation of the efforts of the first round of grantees.

On Thursday I attended first attended the session "Implementation of Mental Health Screening-Strategies and Successes." This program involved early adapters of the MH Guidelines (and some clinics who started doing this before the Guideline Committee formed), sharing with a wide variety of clinics about what to expect going forward with the new CFF Mental Health Guidelines. Some of the feedback from the presenters was the amount of very positive feedback they received from patients and parents of children with CF who were screened for anxiety and depression. Significant challenges include making sure a full slate of treatment options are available and accessible if required after screening.

In the afternoon, I attended the session "Partnering with Patients and Families to Promote Healthy Lifestyles" This focused on maximizing quality of life, diet/nutrition, exercise, and mental/emotional wellbeing. It especially addressed mindful strategies for coping with CF related stress and anxiety, exercise – including psycho-social benefits, and holistic modalities that go hand in hand with our medical regimen. I do think more could have been said about the benefits of a serious commitment to aerobic exercise, but overall, it was an excellent session, perhaps my favorite, and one I would encourage everyone to watch in the NACFC archive. I think it offers a lot to people with CF, as well as their friends and families.

The Thursday Plenary was dedicated to "Personalized Medicine" and advancements being made along the line of CF mutation specific/ mutation class specific pharmaceuticals such as Kalydeco, Orkambi, etc. My only comment about this session, other than the potential of these drugs to help many people with CF, is that it would have been better titled "Individualized Medicine." Personalized Medicine requires addressing the whole person – physical and mental health, and respecting the individual choices and desires of the patient, etc.

Report on my 2015 NACFC experience

by Chris Kvam

Friday's highlight was the "Working Together: Pediatric and Adult Centers Collaborating." This workshop focused on issues surrounding transition from pediatric to adult care, and the transfer of care from one setting to the other. It raised a lot of issues about what transition means, and what it's goals should be. I think there is still a lot of work to be done about defining and implementing better transitions, and I'm glad it is being talked about.

I also attended a working group of social workers who discussed the wide variety of needs they saw within their clinics, and their struggles to address them. One social worker, I believe in Tennessee, started a food bank to help families deal with food insecurity. Another spoke about an inpatient arts program that her health system had implemented, and that they worked with to have their children with CF safely participate in. Overall, the message was quite overwhelming about the challenges the clinics and their patients/families face, and spoke to the impact of poverty and lack of access to affordable health care on their populations.

There were so many sessions to choose from Saturday – they included "Managing the Complex Needs of the Adult CF Patient," "Update on Exercise," "Managing the Maze of Medication and Access Programs", "Psychosocial Needs for the Newly Diagnosed Patient: Pediatric and Adult," and "The Impact on CF on Relationships throughout the Life Span." Ultimately, I chose the Exercise Update, given my personal talents at managing the needs of the adult with CF, and the Managing the Maze of Medication Access.

The exercise update was ok – it is very clear that there is no standardized approach to exercise across CF clinics, and how exercise is approached within clinics is also not always consistent. The overview of the benefits of exercise was powerful. As someone who has made exercise the cornerstone of my CF self-care it was affirming to see this information presented, but also frustrating to see the disparity and barriers that exist to making this a more significant point of emphasis. The challenges are real – exercise is often seen either as an undesirable chore or as an optional, added bonus to a day. It doesn't carry the same urgency of prescribed nebulized therapies, which are more often interpreted as "must do," and yet exercise is no less important, and it's benefits are often clearer and more immediate. Some of the clinicians presenting called for VO2 Max testing within CF clinics, and there was a separate session dedicated to how to interpret exercise testing results. I don't know how I feel about this... part of it seems unnecessary to me, but, on the other hand, I believe that it would show some people with CF and their parents who might think that they are unable to exercise that they are physiologically capable of exercise, and have to build fitness. Fitness = survival.

The Managing the Maze of Medication and Access session was very nuts and bolts, directed at clinical social workers sharing what works best for them in clinic managing these programs and trying to get their patients enrolled. As always, increased patient awareness of available programs was seen as a significant help, as they were most likely to participate and enroll themselves, removing some burden from the social workers.

I had a wonderful time at 2015 NACFC. It was a chance to learn, share, and celebrate the work of the last few years. Thank you for making it possible for me!

Chris Kvam