In June 2015, our CF Center’s pediatric program was one of 15 centers selected to participate in a quality improvement project called the Fundamentals Learning and Leadership Collaborative (LLC). The “Fun LLC” is sponsored by the Cystic Fibrosis Foundation and is designed to help CF Centers improve medical care and outcomes for CF patients. We put together a multidisciplinary team to work on this quality improvement project, which includes pulmonary doctors and nurses, a nutritionist, and a social worker, as well as a patient with CF and the parent of a patient with CF.

Our first task was to assess how our center is doing on five key measures, called the 5Ps. Specifically, we looked at our patients, our professionals, our processes, our patterns, and our purpose. Looking at our first measure, our patients, we found the following.

- This is the patient breakdown by age in the pediatric clinic:
These are the results of our most recent patient satisfaction survey:

- The median FEV₁ percent predicted for our pediatric patients has steadily increased since 2005:

**Median FEV1 Percent Predicted for 6-17 years, 2005-2014**

FEV₁ is the amount of air that is blown out in the first second of the pulmonary function testing.
The BMI percentile in patients 2-19 years of age has also steadily increased since 2005:

BMI is body mass index. This measurement includes weight and height. The CDC (Centers for Disease Control) has BMI growth charts for children who are 2 to 20 years of age. Under 2 years of age, we use weight for length.

However, the weight for length in children under 24 months of age has been more variable, as you can see from the chart below:
You may have seen that there is a big emphasis on nutrition during clinic visits. Why is this? The reason goes back to an analysis performed prior to 2005 in which pulmonary function (as measured by FEV\textsubscript{1}) was graphed against BMI. The data came from a very large number of individuals with CF in the Cystic Fibrosis Foundation Patient Registry:

![Males - FEV1 Percent Predicted vs BMI Percentiles](image)

This data shows that the FEV\textsubscript{1} improves as the BMI percentile increases to the 50\textsuperscript{th} percentile. Thus, the CF Foundation states that for children who are 2-20 years of age, we should strive for a minimum BMI of the 50\textsuperscript{th} percentile. Because the CDC does not have BMI growth curves for under 2 years of age, we use the weight for length growth curve in children under 2 years of age. The principle is the same for children under 2 years of age. We believe that the lungs are healthier with better nutrition.

While we were overall pleased with the results for our patients, we noticed two areas that could stand improvement. We are currently:
- Working to decrease the amount of time families spend in the waiting room.
- Exploring factors that have led to a lack of a steady improvement in weight for length in children under 24 months of age.

You may have noticed some changes already. Other changes are taking place behind the scenes:
- We have added a daily pre-clinic meeting so clinic team members can review each patient’s medical chart and discuss how to make the clinic visit as effective as possible.
- We are taking multiple length measures on 0-2 year old patients. This gives us a more accurate picture of each child’s weight to length, allowing us to better tailor our nutritional recommendations.
We are preparing targeted intervention plans for all patients who have a weight to length less than the 50th percentile. As part of this plan, we may recommend that you keep a 3 day food record for your child. The dietitian will call 2 weeks after your visit to see how things are going and, if needed, work with you to develop a new intervention plan. The food record will be used to assess calorie intake and to help find ways to add calories.

- The parent on our team has written a letter to families who are thinking about getting a feeding tube for their child. We hope this letter will give you a different perspective about this treatment approach.

- We are developing a handout to share with curious or questioning friends and family members who may not understand why we are so aggressive when it comes to nutrition and weight gain.

We would love to know what you think about this project and we are happy to address questions or concerns you might have. We would especially appreciate any ideas or thoughts you have for improving the care for children at our clinic. Please feel free to share your thoughts with us below. You can leave this form in the clinic room or give to the scheduler if you would prefer for it to remain anonymous. Alternatively, you can discuss your ideas with any member of your care team at your convenience. You can call the clinic at (608) 263-6420 to discuss any questions or concerns and/or send a My Chart message.

Please write any comments or suggestions in the space below.