

## Mission statement

Our Cystic Fibrosis Center's mission is to provide excellent patient care while partnering with patients and their families to enhance quality of life, promote education, increase public awareness of the many challenges that patients with CF face, and make meaningful contributions in the search for a cure by participating in clinical trials that evaluate new therapies for treating patients with CF.

## Finding a Purpose for Living with Cystic Fibrosis

*by Jayme Engen*

I live with Cystic Fibrosis, but you would not know it if you met me on the street or spent a day in my shoes. I am thirty-two years old, married, and have been teaching elementary school physical education for ten years. Living with Cystic Fibrosis is not an easy task, but by keeping a positive mindset and always putting your health first, you can accomplish anything while living a normal life.

I struggled with CF a lot in my teen years. There were days when I wondered why I was chosen to have CF when the chances were astronomical that I could be born with this wicked disease. I spent many nights in my room crying and feeling sorry for the situation that I found myself in. Only my closest friends knew I had CF, and I was bound and determined to live a normal life and keep it that way! I was a three sport athlete in high school competing in cross country, basketball, and golf. I even won athlete of the year at my division three high school. All this activity in high school helped my lungs to be in good shape and I was rarely in the hospital, other than my routine clinic visits. I had many friends in high school in different sports and was in what you could call a middle class when it came to popularity. My life was normal and no one saw me any differently in high school. It was time to move onto the next chapter of my life, which was college.

I attended the University of Wisconsin Stevens-Point for five years and received my teaching degree in physical education and health education. During my college years, I was a normal college kid with a normal life, but I would neglect my therapies at times along with medicine and figured my lungs would be ok, because they always were. I was twenty-one and headed in for a normal clinic visit, and was admitted to the hospital for a two week stay, because my lung function had dropped significantly. At this point in my life I had a choice to make. I can either live my life in a hospital, or do the things that I love to do and enjoy life! I chose the latter and was bound and determined to put my health first in order to accomplish what I wanted with my life. I had to stay on top of my medications and therapies and always make time for them. Since making that change, I live a great life as a happily married man, elementary teacher, and high school girls basketball coach.

Putting my health first has allowed me to take care of me and add perspective to my life. It has given me a challenge to conquer everyday and a purpose of beating this disease, while living a normal life. My work and other activities take a back seat to my health, because without my health I cannot do the things that I love! It allows me to prioritize events in my life and lessens stress, because my ultimate goal is to stay healthy and enjoy life. The more I think about it, I was put on this earth with good reason to have CF and inspire people to overcome challenges and obstacles in their lives. The greatest part of all is that 99% of people I walk by everyday have no idea that I have CF, because I choose to take the positive mindset of beating this disease without letting the world know of my everyday challenges or throwing a pity party for myself. Everyone in life has their own set of challenges, and CF happens to be my personal challenge. I understand that others may have a tougher situation than myself as well and that helps put it in perspective. What if I was paralyzed? What if my brain did not function? I choose to take CF for what it is and live with the challenge of defeating it. I try hard to live my life as normal as possible, but I can only do that when I put my health first! Go out and conquer your challenge today!

## **Update on CFF Learning and Leadership Collaborative Grant to Improve Nutrition Outcomes in the 0-2 Year Old Population**

The Pediatric CF Center at American Family Children's Hospital was awarded a Learning and Leadership Quality Improvement (QI) Grant from the CF Foundation (CFF) in June 2015 to focus on a nutrition or pulmonary QI project. The first task was to examine our patient registry data. A review of our data showed a downward trend in nutritional outcomes in our 0-2 year old population. The mean weight to length in 2006 was close to the 75th%ile whereas the mean weight to length in 2014 was right at the 50th%ile. If the downward trend continues, weight to length will fall below the CFF goal of having a mean weight to length at the 50th%ile or above on the CDC Growth Charts.

With the support of the LLC Grant and a QI Coach, therefore, we decided to work on optimizing the nutrition status in this population. By working on this process we will improve weight to length or BMI and eventually FEV1. The positive relationship between weight and lung function is well known. Many studies have also shown that the earlier a healthy weight to length is achieved, the healthier people are in the long run.

Over the past year we have either completed or are in the process of completing several Plan-Do-Study-Act cycles (PDSA) to achieve our goal.

We have:

- 1). Added a pre-clinic huddle to review all of the patients coming in for the day.
- 2). Standardized length measurements in clinic - infants are hard to measure and getting a false high length measurement can send parents the wrong information about how their child is growing,
- 3). Checked in over the phone between clinic visit to see how our recommendations are going and to ask about completion of a food record if necessary.
- 4). Provided written material for parents of children with CF on the importance of BMI and how it positively correlates to lung function.
- 5). Had a family member develop a letter about tube feedings for families.

We are currently working on several projects to reduce exposure to germs which leads to healthier patients with hopefully a better weight:

- 1). Improving timeliness of rooming patients with CF when they arrive for clinic.
- 2). Improving cleaning and sanitizing of clinic rooms.
- 3). Enforcing the use of gowns, gloves, and masks outside the exam room.

Although this QI project is still in progress, to date our mean weight to length has increased to 63.56% and average calorie intake has improved 30%. We hope this success continues.

We feel that we should constantly be striving to improve the care of people with CF. Having dedicated time to meet and work on a

QI project with the help of a coach has enabled us to bring several ideas into reality overall benefitting the nutritional status, and in the long run the lung function of patients with CF. We plan to continue our work even after the grant ends and would welcome any questions, comments, or ideas you may have.

### **CF Team Member Highlights**

We are excited to announce that Dr. Catherine Decker, the Adult CF Program Pharmacist, has been chosen by the Cystic Fibrosis Foundation as a Pharmacy Mentor for the upcoming 2-year term. As a CF pharmacy mentor, Dr. Decker will be matched with a CF pharmacist from another CF-accredited center and will provide resources and information for those that are new to the field of CF with the goal of improving the quality of care delivered. Dr. Decker has been a wonderful addition to our multidisciplinary team for the past 15+ years and we are so proud that she is representing our program and teaching future CF pharmacists! Congratulations Catherine!

### **CF Family Education Day**

In the past, we have had CF Family Education Day in the fall. This year, we have decided to conduct CF Family Education Day in the spring. For the past two years, the staff from the CF Centers in Madison, Milwaukee, La Crosse, Marshfield, and Green Bay have gathered to share their best practices with each other. These five centers will be working together to present a CF Family Education Day in 2017. The location and date are yet to be determined. We will inform you soon of the details.

### **CF and School**

Dear Patients and Families,

The new school year is among us. We hope everyone is settling in to your new school routine. Whether it is preschool, kindergarten, transitioning to a new school or attending college, the cystic fibrosis community has a multitude of resources available. The best place to get started is to go to the CFF.org website. Click on "Living with CF" and then click on "CF and School". There you will find numerous resources from working with your child's school, to managing CF in college, to resources for teachers, administrators, school nurses and coaches.

If you do not have access to a computer we are happy to provide this information to you when you come to clinic. It comes in a red folder and is filled with information regarding CF and Schools.

There are also several educational videos on CF for school personnel on YouTube. Simply search "CF and Schools". We recommend you watch them first and then decide if it is something you want to share with your school. A great video to start with is entitled "Helping Kids with Cystic Fibrosis Succeed in School". It is approximately 7 minutes long.

If you haven't already done so, we encourage you to request a school medication form from us that allows your school to administer any medications that you or your child may require during the school day.

If you have any further questions or concerns regarding CF and School, simply ask any one of us in the CF clinic.

*Thank you and enjoy the new school year!*

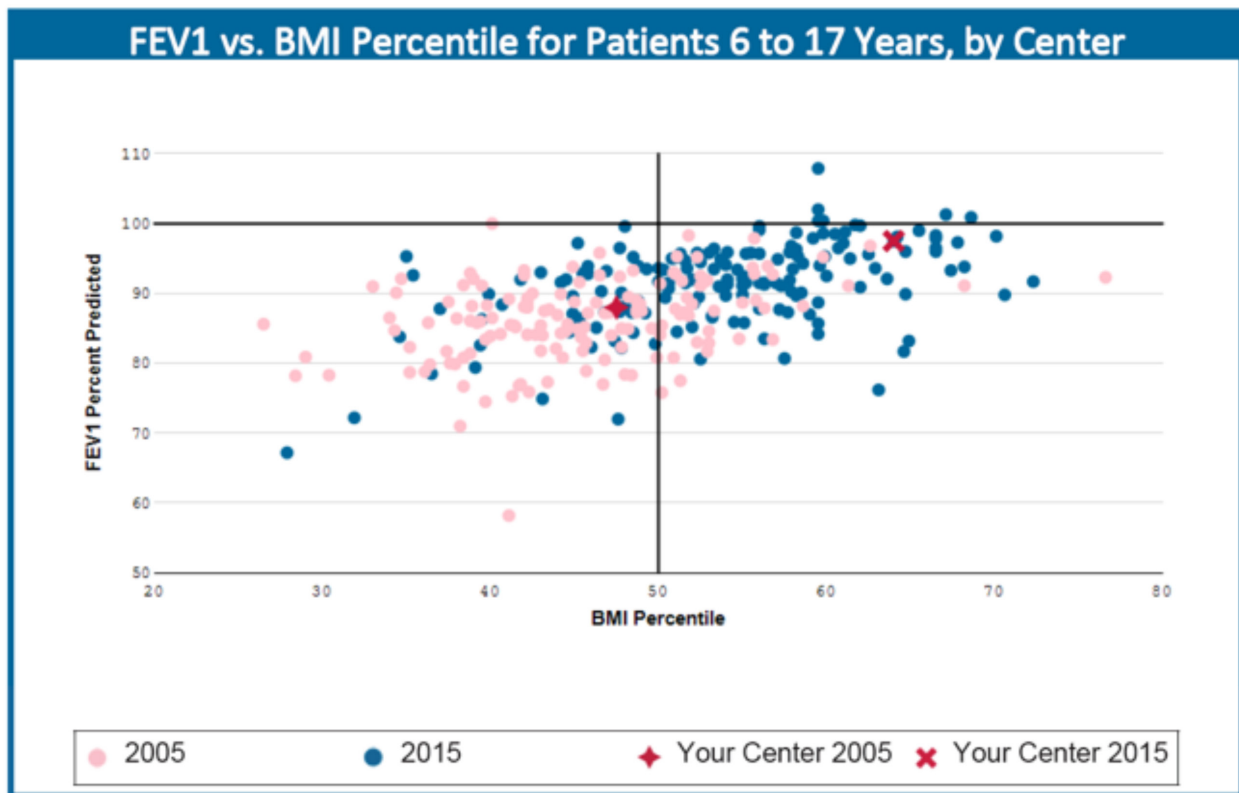
## Trends over the last four years

The following table shows data for the past four years. The UW CF Center specific data is shown first, followed by the national average in parenthesis. This allows you to see trends that are occurring both on a local and a national level.

	2015 UW (national average)	2014 UW (national average)	2013 UW (national average)	2012 UW (national average)
Median FEV <sub>1</sub> % predicted 6-12 years	101.4 (96.4)	99.1 (96.2)	100.5 (95.2)	99.7 (97.9)
Median FEV <sub>1</sub> % predicted 13-17 years	92.7 (87.7)	93.3 (87.2)	90.9 (86.4)	93.1 (90.8)
Median FEV <sub>1</sub> % predicted 6-17 years	97.5 (92.9)	96.8 (92.5)	94.8 (89.2)	98.6 (95)
Median FEV <sub>1</sub> % predicted 18-29 years	79.3 (73)	74.4 (72.7)	78.3 (72.3)	74.8 (71.9)
Median FEV <sub>1</sub> % predicted >30 years	50.0 (59.6)	50.1 (58.6)	51.9 (57.9)	47.4 (57.9)
Median BMI percentile 2-19 years	64 (54.6)	61.5 (53.9)	58.7 (53.3)	59.3 (52.8)
Adults over 20 years of age: % males with BMI >23 and females BMI >22	49.1 (48.8)	43 (47.9)	43.2 (46.5)	44.7 (45.7)

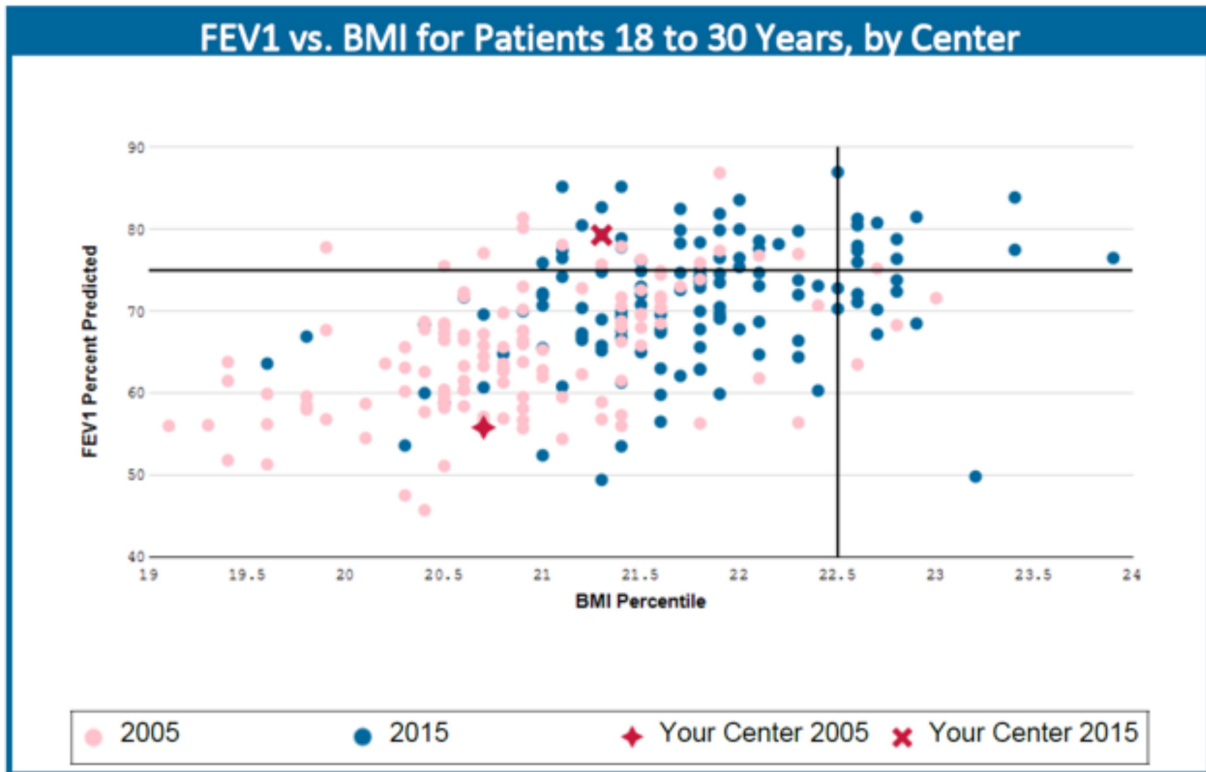
Of note is that in 2013, the CF Foundation started using the Global Lung Initiative reference equations. (The previous reference equations were by Wang and Hankinson.) This change results in lower FEV1 percent predicted values for preteens and teens.

Similar to last year, the CF Foundation provided a graph to the care centers in which FEV1 %predicted is plotted against BMI. Here is the graph for 2015 for the pediatric program:



Each pink circle is center data for 2005 and each blue circle is data from 2015. The UW CF Center data from 2005 is indicated by the star sign, and the UW CF center data from 2015 is indicated by the 'x'. The vertical line is the CF Foundation goal of a BMI of at least the 50th percentile and the horizontal line is the CF Foundation goal of an FEV1 of at least 100% predicted. Centers with improved outcomes have symbols that are up and to the right. As you can see, there has been a significant shift in a good direction for the UW pediatric program.

Here is data for the adult program:



The symbols are the same as for the pediatric program, namely that the UW CF Center data from 2005 is indicated by the star sign, and the UW CF center data from 2015 is indicated by the "x". The vertical line is the CF Foundation goal of a BMI of at least the 22.5 kg/M<sup>2</sup> and the horizontal line is the CF Foundation goal of an FEV1 of at least 75% predicted. Like the pediatric data, there has been significant improvement over the past decade.

## Orkambi® approved for patients 6-11 years of age

On September 28, 2016, the U.S. Food and Drug Administration approved Orkambi® (lumacaftor/ivacaftor) for cystic fibrosis patients who are 6 to 11 years of age and who have two copies of the F508del mutation. The approval was based on data presented at the European Cystic Fibrosis Conference in June in Basel, Switzerland. At that conference, the results of an open label phase 3 trial in 58 children who were 6-11 years of age and who had two copies of F508del were presented. The primary endpoint of this study was safety and Orkambi® was well tolerated in those children. At 24 weeks, there were improvements in multiple secondary endpoints, including a reduction in sweat chloride of -24.8 mmol/L, a weight gain of 2.6 kg, an improvement in the Cystic Fibrosis Questionnaire-Revised respiratory domain score of 5.4 points and an absolute improvement in FEV1 of 2.5 percentage points. (please see the Vertex press release at [http://files.shareholder.com/downloads/VRTX/2786823278x0x896062/FF111F3F-6097-4295-82DC-7D7DB988C2A3/VRTX\\_News\\_2016\\_6\\_10\\_General.pdf](http://files.shareholder.com/downloads/VRTX/2786823278x0x896062/FF111F3F-6097-4295-82DC-7D7DB988C2A3/VRTX_News_2016_6_10_General.pdf)).

This is an important milestone in CF care. It makes sense to treat the basic defect at an early age in an attempt to prevent the progression of lung disease. There is an ongoing study of using Orkambi® in children who are 2 to 5 years of age (Safety and Pharmacokinetic Study of Lumacaftor/Ivacaftor in Subjects Aged

2 Through 5 Years With Cystic Fibrosis, Homozygous for F508del; <https://clinicaltrials.gov/ct2/show/NCT02797132?term=VX15-809-115&rank=1> and <https://www.cff.org/Trials/Finder/details/469/Phase-3-study-of-lumacaftor-ivacaftor-in-children-with-CF>).

### Why Participate in a Clinical Trial?

(reprinted from <https://www.cff.org/Our-Research/Clinical-Trials/Clinical-Trials-101/Why-Participate-in-a-Clinical-Trial-/>; additional information available at this web site including a video of a CF patient participant in a clinical trial and a video from a CF researcher).

There have never been more opportunities to help develop new drugs for CF than there are today. Because of all the promising new research opportunities, as many individuals with CF as possible are needed to participate in clinical trials

Under-enrollment is one of the biggest challenges for researchers, and it can slow the development of a potential treatment. Because there are only around 33,000 people with CF in the United States, there is a limited pool of people to draw upon for a clinical trial. That is why it is critical that those who are interested and able to participate find an appropriate clinical trial.

## The Benefits of Participating in a Clinical Trial

Participating in a clinical trial can be a very satisfying and worthwhile experience. People with CF choose to participate in clinical trials for a number of different reasons. Some possible benefits include:

- Taking an active role in managing your own CF care
- Gaining access to new treatments before they are more widely available
- Getting free expert CF care at CF Foundation-accredited health care centers
- Helping advance our knowledge of CF
- Receiving a treatment that works for you or your child

## Clinical Trials at the University of Wisconsin

We are recruiting for the following clinical trials at the University of Wisconsin:

### SHIP: Saline Hypertonic in Preschoolers

The purpose of this study is to assess whether inhalation of 7% hypertonic saline (HS) twice daily for 48 weeks improves the lung clearance index by multiple breath nitrogen washout in comparison with inhalation of 0.9% isotonic saline (IS) in preschool children (ages 3 to 5) with cystic fibrosis. The main entry criteria is age of  $\geq 36$  months and  $\leq 72$  months. Patients are not eligible if they have received nebulized hypertonic saline within 30 days prior to screening.

If you are interested in this study, please contact one of the pediatric research coordinators:

Linda Makhholm at 608-262-0340 or Melanie Nelson at 608-265-4617

### SNO-7: Study of N91115 in CF Patients Who Are Heterozygous for F508del-CFTR and a Gating Mutation and Being Treated With Ivacaftor

The purpose of this study is to assess the effect of N91115 on lung function when added to preexisting treatment with ivacaftor in adult patients with CF who are heterozygous for F508del-CFTR and a gating mutation that is approved for treatment with ivacaftor (G551D, G1244E, G1349D, G178R, G551S, S1251N, S1255P, S549N, or S549R). The main entry criteria are the mutations in the previous sentence and patient age must be  $\geq 18$  years.

If you are interested in this study, please contact one of the adult research coordinators:

Sophia Chiron Stevens at 608-263-1244 or Amy Amessoudji at 608-263-3336

## A Study to Evaluate the Safety and Efficacy of VX-371 in Subjects With Cystic Fibrosis Who Are Homozygous for the F508del-CFTR Mutation

This study is assessing the safety and effectiveness of VX-371 (formerly P-1037) in patients who have two copies of F508del and who are already receiving Orkambi®. VX-371 is an inhaled medication that blocks the sodium channel. By blocking this channel, the drug may prolong the duration that fluid in the airways can be maintained after hypertonic saline use. The main entry criteria is two copies of the F508del mutation, already receiving Orkambi® and patient age must be  $\geq 12$  years.

If you are interested in this study, please contact one of the adult research coordinators:

Sophia Chiron Stevens at 608-263-1244 or Amy Amessoudji at 608-263-3336

## Effect of GS-5745 on FEV1 in Adults With Cystic Fibrosis

GS-5745 is an anti-inflammatory drug that is injected subcutaneously on a weekly schedule. The purpose of the study is to assess the change in FEV1 percent predicted. The main entry criteria are age  $\geq 18$  years and FEV1 percent predicted must be between 40% and 80%.

If you are interested in this study, please contact one of the adult research coordinators:

Sophia Chiron Stevens at 608-263-1244 or Amy Amessoudji at 608-263-3336

## A Study to Evaluate the Safety, Pharmacokinetics, and Pharmacodynamics of Ivacaftor in Subjects With Cystic Fibrosis Who Are Less Than 24 Months of Age and Have a CFTR Gating Mutation

This study will administer Kalydeco® (ivacaftor) to children with CF who are  $< 24$  months of age and who have a gating mutation (G551D, G178R, S549N, S549R, G551S, G1244E, S1251N, S1255P, or G1349D). The primary outcome measures are safety and the concentrations of ivacaftor in the blood.

If you are interested in this study, please contact one of the pediatric research coordinators:

Linda Makhholm at 608-262-0340 or Melanie Nelson at 608-265-4617

## News from the Wisconsin Chapter of the Cystic Fibrosis Foundation

We would like to thank all of our donors, volunteers, families and fighters for your dedication and generosity in the past few months! We've had an exciting Summer, and Fall looks to be equally exciting.

On September 28th, the US Food and Drug Administration (FDA) approved the use of lumacafor / ivacaftor (Orkambi®) for children with cystic fibrosis ages 6 to 11, who have two copies of the F508del mutation. The decision means that about 2,400 additional children in the US are eligible to receive the drug, bringing the total number of those eligible for the treatment in the US to nearly 11,000! In people with two copies of F508del, lumacaftor/ivacaftor improves lung function and significantly reduces the rate of pulmonary exacerbations, which can lead to frequent hospitalizations and accelerated lung disease. Vertex is looking to expand access to the drug further by conducting a Phase 3 clinical trial of lumacaftor/ivacaftor in children ages 2 to 5.

We've had a thrilling year with all of our fundraising events, and would like to thank everyone for their support. Our most recent September events, the Breath of Life Gala in Milwaukee and Xtreme Hike Wisconsin in Devil's Lake, helped raise \$378,000 collectively! We invite you all to support our last fundraising event of the year, CF Climb MKE, which will take place on November 10. For more information, visit <http://fightcf.cff.org/WIClimb>.

As the year begins to wrap up, so does the 2016 Annual Fund. Thank you to our Annual Fund donors who have already committed a gift in 2016. As you make plans for your year-end giving, please remember the CF Foundation. We are extremely fortunate to have an additional incentive for your support. For the second year in a row, Marlin Oil Corporation is pleased to offer a special matching gift opportunity to encourage more people to support the Foundation's Annual Fund program. Once our chapter reaches its Annual Fund fundraising total from last year – \$50,091.19 – Marlin Oil Corporation will match every additional contribution (between \$1 and \$9,999) received from all Foundation chapters by December 31, 2016, dollar for dollar, up to a total of \$500,000. Our current total is \$30,740. You can make a 100% tax-deductible donation by visiting <http://www.fightcf.cff.org/wisconsin-anf>.

Thank you again for all that you do, and please feel free to contact us with any questions, comments, concerns, or suggestions!

Yours for a Cure,



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## Cystic Fibrosis Center Specific Outcomes

Here is our center specific data for the calendar year 2015. There is publicly available data on all Cystic Fibrosis Centers available at the Cystic Fibrosis Foundation website ([www.cff.org](http://www.cff.org)). Data on that website is adjusted for attained age of patients, gender, pancreatic sufficiency, race/ethnicity, socio-economic status, and age of diagnosis. As of the writing of this newsletter, the CFF website has not yet been updated to include the 2015 data. We expect that data to be publicly available in the near future. In the meantime, we now have our UW CF Center data for last year, and what follows in this article is the raw data reported to us for the calendar year 2015.

### Pediatric Program

A very useful measure of lung function is the FEV1 percent predicted. For patients 6-12 years of age, the University of Wisconsin CF Center median FEV1 percent predicted is 101.4%, which is 5% above the national average of 96.4%. For patients 13-17 years of age, the median FEV1 percent predicted is 92.7 % at UW compared to a national median of 87.7%. For patients 6-17 years of age, the UW median FEV1 percent predicted is 97.5% compared to a national median of 92.9%.

Our nutritional outcomes are expressed in terms of BMI (Body Mass Index) percentile. For pediatric patients 2-19 years of age, we strive for a BMI percentile of at least the 50th percentile. The median BMI percentile for CF patients 2-19 years of age at UW was 64.0 compared to a national average of 54.6.

### Adult Program

For patients 18-29 years of age, the median FEV1 percent predicted at UW is 79.3% compared to a national average of 73.0%. For CF patients > 30 years of age, the median FEV1 percent predicted at UW is 50.0% compared to a national average of 59.6%.

In adults over 20 years of age, one no longer uses BMI expressed as a percentile. In adult patients, BMI is expressed as the actual value with the units of kilograms per meter squared. The Cystic Fibrosis Foundation goal is that males should have a BMI of greater than or equal to 23 kilograms per meter squared and females should have a goal BMI greater than or equal to 22 kilograms per meter squared. In the UW Center, the percentage of adult patients who met those goals was 49.1% compared to the national average of 48.8%.

## YOUR CF CLINIC VISIT

Our goal is to see all of our CF patients on a quarterly basis at a minimum, and while we understand that sometimes these visits and associated testing may be long and overwhelming, there is a method behind our madness! As an accredited Cystic Fibrosis Care Center, your multidisciplinary team is devoted to giving you/your child the best care possible. Therefore, we recommend evaluation and treatment recommended in CF clinical care guidelines which are based on the best medical evidence and practices.

Along with at least four visits per year with a cystic fibrosis specialist who will be monitoring you closely and adjusting your treatment regimen as necessary, there are multiple other recommendations that we follow which are summarized in the charts below.

**CFF Guidelines for Frequency of Evaluation/Tests for patients with CF**

Evaluation by Providers with Expertise in the Field of CF	CFF Recommended Frequency		Rationale
	Annually (at a minimum)		
Registered Dietitian	x		Advise and educate about nutritional management in CF including management of overall nutritional status, pancreatic insufficiency and vitamin therapy.
Social Worker	x		Provide holistic care for patients' and caregivers'. They have an excellent knowledge base of the complex system of benefits available to CF patients. They can also help with a wide range of emotional and financial situations and can enhance communication with the healthcare team.
Respiratory Therapist	x		Overview and education regarding inhalational therapies, airway clearance techniques and proper care of equipment.
Pharmacist	Not currently a requirement		While not yet mandated by the CFF, a CF pharmacist will visit most patients on each visit to review medication usage, indications as well as provide ongoing education regarding medication management.

Lab/Procedure	CFF Recommended Frequency		Rationale
	Quarterly	Annually	
Sputum Culture	x		Obtained via throat swab or expectorated sputum. Performed to assess bacterial burden as well as resistance patterns.
AFB Culture		x	
Liver Function Tests		x	Blood tests performed to assess for other CF-related disorders.
Vitamin Levels (A,E and D)		x	
Creatinine		x	
CBC with differential		x	
Immunoglobulin E		x after age 6	
Random glucose		x after age 2	
Oral glucose tolerance test		x after age 10	Glucose intolerance and cystic fibrosis related diabetes (CFRD) are age related complications, occurring more often in CF patients than the general public after age 10, and require specific testing/management and often evaluation by a Diabetes Specialist
Hemoglobin A1c	x if CFRD		
Eye Exam		x if CFRD	
Urine microalbumin ratio		x if CFRD	
PFTs	x		Frequent spirometry and an annual CXR help detect early changes in pulmonary disease.
Chest X-ray		x	
Bone Mineral Density		x after age 8	Bone disease is more common in patients with CF and risk increases with age. A bone mineral density scan will be performed every 1-5 years pending results of prior studies.
Influenza Vaccine		x	Viruses can precipitate CF exacerbations and it is very important to get your routine vaccinations!
Depression/Anxiety Screening		x	Studies have noted high rates of depression and anxiety in CF patients and caregivers. Untreated symptoms are associated with decreased lung function as well as decreased quality of life. All patients 12 years and older should be screened as well as parent caregivers of patients age 0-17 years.

## Pneumovax vaccine

Dear Families,

Flu season is once again upon us. This letter is a gentle reminder of the recommendations regarding vaccines to keep your child as healthy as possible throughout the upcoming flu season. The Wisconsin Immunization Registry (WIR) is an excellent resource to check your child's immunization status. It identifies all vaccines received in the state of WI and what vaccines your child is in need of. The link to the website is: <https://www.dhswir.org/PR/clientSearch.do?language=en>. If your child receives immunizations in a state other than WI, please check with your state's immunization registry.

Listed below are the vaccines that are recommended for your child with cystic fibrosis:

- Annual influenza vaccine (flu shot). This vaccine is recommended for all patients seen at AFCH Pulmonary/CF Specialty clinic each year starting at the age of 6 months. The vaccine can be obtained at your PCP office, AFCH Pulmonary/CF Specialty clinic or in your community. The vaccine is listed as "influenza" in the WIR system.

- Pneumovax vaccine (PPSV 23). This vaccine is recommended for all patients seen at AFCH Pulmonary/CF Specialty clinic starting at the age of 2. If your child has already received this vaccine, they will not need a booster until the age of 65. The vaccine is listed as "pneumo-poly" in the WIR system. If your child has never received this vaccine, they will need to have proof of first receiving 2 doses of Prevnar 13. This vaccine is listed as "pneumococcal" in the WIR system. It is then further described as Prevnar or Prevnar 13. This is a vaccine that most all children received in the first 2 years of life. It is typically a 4 shot series. If your child only received Prevnar, and not Prevnar 13, they will require 2 doses of Prevnar 13 prior to receiving the Pneumovax vaccine. Prevnar 13 can be obtained at your PCP office or at AFCH Pulmonary/CF Specialty clinic. However, your child must receive their last dose of Prevnar 13 eight weeks prior to receiving the Pneumovax vaccine. Therefore, you may want to inquire in advance as to whether your child has received at least 2 doses of Prevnar 13 due to the 8 week waiting period before the Pneumovax vaccine can be administered. This may be something you may want to explore as soon as possible to prevent any further delay in immunizations. If your child is in need of 2 doses of Prevnar 13 prior to receiving the Pneumovax vaccine, this can be obtained at your PCP office.

If you have any questions or concerns regarding the information listed above, please do not hesitate to contact the AFCH Pulmonary/CF Specialty clinic or your PCP office.

*Sincerely, AFCH Pulmonary/CF Specialty Clinic Staff*

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*[www.uwcfcenter.org](http://www.uwcfcenter.org)*