



# MYCYFAPP NEWS

Nº 04 | October 2016 | [www.mycyfapp.eu/es/](http://www.mycyfapp.eu/es/) | [f Mycyfapp](#) | [t Mycyfapp](#) | [v Mycyfapp](#) | [i Mycyfapp](#)

## THE CO-DEVELOPED APP MYCYFAPP IS AIMED AT A PERSONALISED SELF-MANAGEMENT OF PANCREATIC INSUFFICIENCY IN CYSTIC FIBROSIS

MyCyFAPP project aims at developing an APP for self-management of enzyme replacement therapy in children with Cystic Fibrosis (CF) through a personalised and interactive monitoring and learning process.



## 3<sup>RD</sup> MYCYFAPP PROGRESS MEETING

Members of the whole consortium met in Rotterdam (The Netherlands) last June 27<sup>th</sup>, 28<sup>th</sup> and 29<sup>th</sup>. Multi-disciplinary workshops were set up in order to discuss about the results obtained and to make agreements on the way ahead. One of the most relevant presented results was the nutritional recommendation handbook. It aims at providing the most recent evidence-based recommendations in terms of nutrition, in order to empower patients and their families to self manage this important part of their treatment.

The third phase of the project was also presented. This phase consists of the clinical trial that will follow the first two phases of the project: the identification of the nutritional habits and the development of the initial app prototypes.

The clinical trial will be splitted into 2 parts.

The first part involves the administration of two questionnaires regarding gastrointestinal problems of CF patients and their quality of life.

During the second part, when the App will be available, patients will be enrolled to test it.

All partners are working hard and the results are coming out. Stay tuned because MyCyFAPP newsletters will be delivered more frequently, 4 times a year!!



## 2 PROGRESS ON VITRO DIGESTION



## 3 MIDTERM EVALUATION OF MYCYFAPP GAME

**You Tube**

## 4 AN INTERESTING INTERVIEW SERIES IS GOING TO START ON YOUTUBE



### IN VITRO DIGESTION STUDIES KEEP FULL OF PROGRESS IN TESTING FOODS AND MEALS

The Food Digestion for Health (FoodiHealth) team are the MyCyFAPP partners of the University Institute of Food Engineering for Development at the UPV. Currently five lines of experimental designs are aimed at generating knowledge of the optimal dose of digestive enzymes for foods and dishes according to lipids digestion:

- study of the inherent-to-food characteristics
- study of the gastrointestinal environment conditions
- study of the interactions among nutrients and meal factors
- *in vitro* digestion of food groups
- *in vitro* digestion of national traditional meals and dishes

Learn more about this team at the link:

[http://www.iad.upv.es/nuevos\\_alimentos\\_english.html](http://www.iad.upv.es/nuevos_alimentos_english.html)



## DEVELOPING SUPPORT FOR SELF-MANAGEMENT IN MYCYFAPP: TWO VIEWPOINTS, ONE SERVICE

The development of the self-management App for CF patients and parents as well as the web-based management tool for health professionals (HPs) is now well under way. The App and the web-based tool are two viewpoints in the self-management service: the features supported by the App are mirrored in the tool, and conversely. We focus initially on features that are of high priority to patients, parents and HPs, and that are essential for achieving the main project goals.

Enzyme management is a core feature of the App and of the MyCyFAPP project. The App will calculate the recommended personal enzyme dosage for each meal and also record the actual dosage taken. HPs are involved in setting the individual correction factor.

Quick, simple and accurate food recording is essential to describe what each meal consists of. The App will use a database of ingredients and composed dishes as well as personal favorites to assist the user in registration. Food records can be shared with HPs so they can analyze patients' diet.

The App will contain educational content about the disease, treatment and nutrition. The content will be tailored for presentation on mobile devices. HPs can give recommended reading to the users, and can follow the progress of what has been read.

Nutrition management is about helping patients to keep a healthy diet in terms of energy and percentages of fat, proteins and carbohydrates. A set of recommended dishes will be available for the food record and will come with recipes for preparation. Nutritionists will be able to support patients to set up personalized nutrition goals, and will contribute with recommended dishes and recipes.

Diary keeping including keeping track of symptoms is described in more details in this newsletter. HPs will see an overview of the symptoms that the user decides to share with their development over time.

Several other features are also on the drawing board and will be added to the App and web-based tool when the first set of features is working well.

Figure: a screenshot of the diary in the web-based tool

Symptoms	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Heartburn							
Daily frequency	One or two times						
Stomach	at						
Abdominal pain							
Reflux							
Bowel movement							
Bloating and gas							
Daily frequency							
Fullness							
Flatulence		at	at	at	at	at	
Belching							
Appetite							
Vomiting							
Diarrhea							

## CHILDREN AS GAME TESTERS: PREPARING THE MIDTERM EVALUATION OF MYCYFAPP GAME

The technical development of the MyCyFAPP game has reached a big milestone: the game is halfway done! Time to test it with CF children and teenagers again, this time on a larger scale.

In the next few weeks, the midterm evaluation of the MyCyFAPP game will be conducted in form of prototype tests. The tests will be done in Belgium, Germany and Italy. A total of about 14 children and teenagers will be involved, covering all three target age groups: 5-7 years, 8-12 years and 13-16 years.

Following the User-Centered-Design approach, applied on the whole development process of the MyCyFAPP project, users are not only involved in the first idea and conceptualization phase of the project, but are also asked for their feedback on different versions of the game prototype.

As “product tester” or “game tester” the involved children and teenagers are asked to try out the intermediate version of the game and to comment on what they are seeing and doing. All interactions with and reactions on the game of the young users are observed. After trying out the game, depending on the age of the test user, they are asked for comments about what they liked and didn't like about the game, for ideas about what and how to improve the game and to rate the current version of the game app.

Goal of the midterm evaluation is to check if the game app is easy to use for all age groups, if the content of the game is comprehensible for all ages and, most important, if the young patients enjoy playing the game.

The prototype tests will offer insight about what and how to improve certain parts of the game but also will provide a first rating of the game through possible end-users, that can later on be compared with the rating of the final version. This allows determining the improvements of the app along the development process.

Stay tuned; soon we will share the results of the midterm evaluation with you.



smiley scale, used for the rating of the game

## GEMINI MAGAZINE SEPTEMBER 2016



### RARE DISEASE CHALLENGES ICT RESEARCHERS

People with cystic fibrosis (CF) need help to ensure they are getting correct nutrition and the right amount of enzymes. They also need constant reminders. Researchers are now developing a digital support device to promote autonomy, but are finding that this is no easy task.

<http://geminiresearchnews.com/2016/09/rare-disease-challenges-ict-researchers/>

## VII Conference of Training and Update in Cystic Fibrosis

18<sup>TH</sup>-19<sup>TH</sup> APRIL 2016, BUENOS AIRES, ARGENTINA

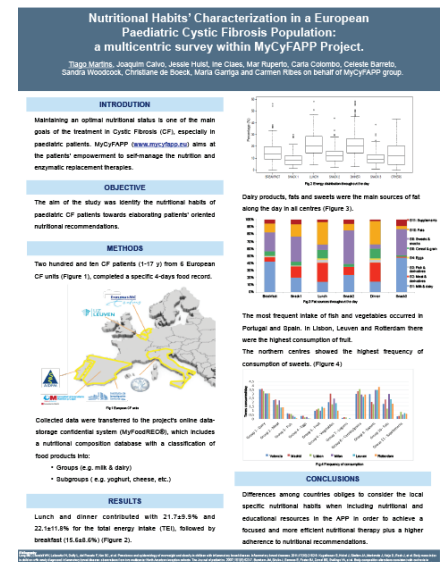
MyCyFapp project was presented by María Garriga (SERMAS) at this meeting organized by Argentina Cystic Fibrosis Association (FIPAN)



## ECFS 39<sup>TH</sup> CONFERENCE

8<sup>TH</sup>-11<sup>TH</sup> JUNE 2016, BASEL (SWITZERLAND)

- Tiago Martins (AIDFM) presented the following poster: “Nutritional habits’ characterisation in a European paediatric cystic fibrosis population: a multicentric survey”. <https://www.ecfs.eu/conferences/basel2016>



- Joaquim Calvo Lerma (HULAFÉ) made an oral presentation on: “Nutritional status, nutrients intake and enzymatic supplements in a European Cystic Fibrosis Cohort: a cross-sectional overview”



## CURRENT STATUS OF THE GAME APP: THERE'S A MONSTER ON THE ISLAND!

Finally, the game app has the hero: a nice and funny monster, living on an island with other fantastic characters, taken from the sea world.

In this scenario, children can play different mini-games and interact with the environment and all the characters, increasing their own knowledge about nutrition and healthy behaviours.

The game app has been tested before the summer and thanks to the feedback collected, both with patients and clinicians, a new version of the game app is now developed.



The updated release includes graphic elements, as the island and the avatar's house; game elements, as the possibility to customize the avatar and learning elements, as the first mini-game related to macronutrients (carbohydrates, fats, proteins).

### COMING SOON

**MYCYFAPP 4<sup>TH</sup> PROGRESS MEETING**  
16<sup>TH</sup> - 18<sup>TH</sup> JANUARY 2017 IN  
VALENCIA (SPAIN)



## AN INTERESTING INTERVIEW SERIES IS GOING TO START ON YOUTUBE

## SOCIAL NETWORKS:

TO STAY UP TO DATE FOLLOW US ON OUR SOCIAL NETWORK PAGES: "MYCYFAPP". WE DAILY POST NEWS RELATED TO CF, NUTRITION AND OUR PROJECT. MYCYFAPP WILL LAUNCH AN EXCITING COOKING CHALLENGE...STAY CONNECTED AND SHARE WITH US THIS EXPERIENCE. SOON WE WILL BE ON LINKEDIN TOO.



## THE MYCYFAPP CONSORTIUM

We are a multidisciplinary research team, integrated by nutritionists/dieticians, paediatric gastroenterologists and pulmonologists, food technologists and engineers. IT experts, game developers, software developers, psychologists, biologists and patients' representatives who will bring their expertise to ensure the successful development of the project through a holistic and integrative approach of the different and complementary areas of knowledge and experts included.