



# MYCYFAPP NEWS

Nº 03 | May 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 AND ACCURATE CONTROL AND MONITORING OF THE DISEASE

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.



## THE EUROPEAN COMMISSION RATES MYCYFAPP PROGRESS AS "EXCELLENT".

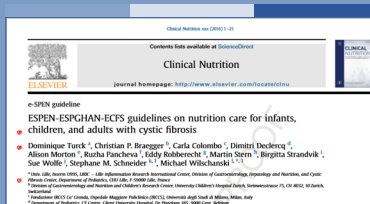
MyCyFAPP first review took place at the European Commission headquarters in Brussels on 9<sup>th</sup> of February, 2016. The panel of experts, composed by an Expert in Nutrition and Eating Behaviour (Greece), an Expert in Innovation (UK) and an Expert in Augmented Reality (Germany), rated our work as "excellent". The session consisted on WP leaders of the Project presenting the progress achieved to date. The overall evaluation criteria were focused on degree of fulfilment of the Project objectives and activities, the use of resources and the quality of the results obtained.

Two were the main scientific achievements obtained during the first year of the project: a survey on nutritional habits among European CF patients and a series of vitro digestion studies to establish pancreatic enzymes requirements with specific meals.

Project consortium was encouraged to "keep ambitious" and to enhance dissemination and publication of scientific papers. Panel remarks such as "excellent technical progress has been made so far", "the quality of the results is very high" and "all objectives, deliverables and milestones for the period were attained" led to the Project Officer's green light to continue with the Project with no modifications.



**P2** SEE THE POSTER AND VIDEO  
WITH THE STUDY DESCRIPTION  
AND JOIN US.



**P4** NEW GUIDELINES ON NUTRITION  
CARE FOR INFANTS, CHILDREN  
AND ADULTS WITH CF.



**P4** AN INTERESTING INTERVIEW  
SERIES COMING SOON ON  
YOUTUBE. STAY TUNED!



## 2<sup>ND</sup> PROGRESS MEETING TOOK PLACE IN MUNICH IN JANUARY 2016

Members of the whole consortium met in Munich (Germany) last 18<sup>th</sup> and 19<sup>th</sup> of January. Multi-disciplinary workshops were set up in order to discuss about the goals reached and to make arrangements on the main topics that the APP will include.

### NUTRITIONAL RECOMMENDATIONS FOR PATIENTS AND FAMILIES.

The nutritional recommendations were derived from the MyCyFAPP European survey. They are based on nutritional habits and dietary patterns of patients with CF and are adapted to national needs. They will be:

- Focused on addressing the most common nutritional unbalances.
- Full of practical and tangible examples of recommended meals and dishes.
- Integrated in the APP: interactive, multimedia, individually tailored contents.
- Written by experts in CF nutrition and care.



### WHICH IS THE OPTIMAL DOSE OF ENZYMES?

First patients have already joined the pilot study aimed at finding out the optimal dose of enzymes. Participants from all the participating centres will follow the same 24 hour menu. They will try an enzymes dose for each test meal according to the in vitro digestion studies to see how they work in their bodies. The study will last until the end of 2016 in three different stages. To see the video visit "mycyfapp" youtube page.

**RECRUITMENT**

- If you are 1 – 17 years old
- If your doctor considers you can join
- If you belong to Hospital Universitari i Politècnic La Fe

**Then, you are welcome!**

**MyCyFAPP pilot study kicks off its way towards an accurate and personalised adjustment of the enzymatic supplements dose this spring. Are you ready and willing to join the Project?**

**STUDY DESCRIPTION**

1. You will have to follow a standard diet from Friday night till Saturday snack, along with a standard dose of enzymes
2. You will intake red and blue colorimetric markers to dye faeces
3. You will have to collect the faeces according to the colour they have

The test will be repeated during two consecutive weekends, and three times in a year (2016):

Stage 1: March – April  
Stage 2: July – August  
Stage 3: November

Contact: [joaquin\\_calvo@lilafe.es](mailto:joaquin_calvo@lilafe.es)  
[www.mycyfapp.eu](http://www.mycyfapp.eu) | [mycyfapp](#) | [mycyfapp](#)  
Project funded by the eu under grant agreement number 643806

### DIFFERENCES IN NUTRITIONAL PATTERNS AMONG THE PARTICIPATING COUNTRIES.

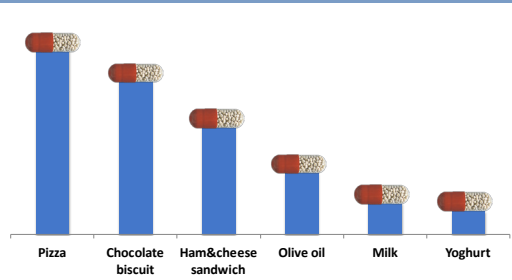
We have found that in Portugal, Spain and Italy main meals consist of several courses with a main carbohydrates-based dish, mainly pasta and rice. On the other hand, in Belgium and The Netherlands, main meals generally consist of one bread-based dish.

Low fish and fruit and high sweets and snacks consumption is the common dietary pattern among all the participants. The most fat-rich meal is dinner in all the countries.





Enzyme doses are needed to fully digest different food products.



## HOW TO DOSE ENZYMES FOR A 24 HOUR MENU?

The in vitro digestion studies carried out at the IIAD-UPV have established the optimal dose of enzymes to fully digest fat of five menus. Different fat digestion kinetics and doses have been determined, these depending on the fat nature and food matrix physicochemical structure. Identified optimal doses for the menus studied are being tested for the first time in MyCyFAPP pilot study, involving CF patients with pancreatic insufficiency. The in vitro characterisation of fat digestion in other food products is ongoing.

## CO-DESIGN INTERACTION WITH CHILDREN.

First prototypes of MyCyFAPP games are being tested in Italy and in Germany. Kids have chosen looks and characteristics of fictional avatars, topics and surroundings.



### Design level of Games

Looks, characteristics of fictional avatars, topics, surroundings

## MYCYFAPP AROUND THE WORLD:

### PEDIATRICS IN CLINICAL PRACTICE

10<sup>TH</sup>- 11<sup>TH</sup> MARCH 2016 MILANO, ITALY

Carla Colombo presented MyCyFAPP project in a session on the use of telemedicine and apps in chronic diseases of children.

### XIII CONGRESS OF THE SPANISH SOCIETY FOR FC

5<sup>TH</sup> AND 7<sup>TH</sup> NOVEMBER 2015 MURCIA, SPAIN

Joaquim Calvo presented MyCyFAPP project at the Spanish Society for CF.

### H2020 REGIONAL INFODAY

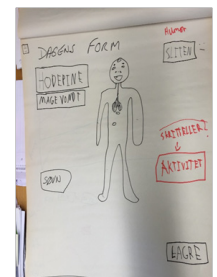
NOVEMBER 2015 VALENCIA, SPAIN

In November 5<sup>th</sup>, Joaquim Calvo presented MyCyFAPP as a success story in the regional infoday in Valencia about key aspects to prepare a proposal for Horizon 2020.

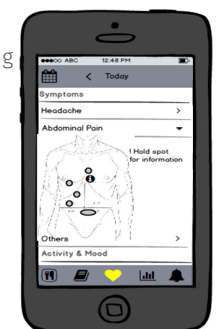
## CO-DESIGN AT WORK.

Co-design workshops were conducted in the Netherlands, Norway, Spain and Portugal in order to ensure that the self-management App under development in MyCyFAPP will fit to the patients' and parents' needs. The goal was to gain understanding on how the App could fit in the daily lives of the users and how the users would like to interact with the App. The workshops have involved different target groups, including teenagers, adults and parents. Also health professionals have contributed to the validation of the results, e.g., the relevance and correctness of content. The main result from the workshops is a set of "mock-ups", i.e. sketches of the user interfaces for the App. The mock-ups relate to the main features selected for the App, i.e., food record and enzyme management, nutrition management, diary keeping and treatment follow-up. They will serve as requirements for the on-going App development. The starting point for the co-design workshops was the set of functional features based on the requirements earlier gathered through interviews. The co-design work was then been conducted in an iterative way. First, paper sketches were drawn by participants in the initial workshops, and formalised by MyCyFAPP Software experts using the mock-up tool Balsamiq. Further, the mock-ups were refined during new co-design workshops. Finally, videos presenting the revised mock-ups were developed and presented to patients, parents and health professionals in order to collect feedback.

From sketch drawn by a patient in Norwegian



to a Mock-up drawn by using Balsamiq.



## MYCYFAPP AROUND THE WORLD:

### SCANNER MAGAZINE

APRIL 2016

REEL IN

#### Controlling Cystic Fibrosis using an app

Each month, a researcher tells us which Horizon 2020 grant has been reeled in and what this means for the research project. This month it is Jessie Hulst's turn. She is pediatric gastroenterologist and member of Sophia Children's Hospital CF team.

**What grant were you awarded?**  
"Full management of health and disease of children and adolescents. The grant is awarded to support research that will contribute to the development of new therapies and devices. A total of 10 million euros has been awarded for the project. We work together with 14 partners from several different countries."



**What will happen in the coming years?**  
"To test the MyCyFAPP app as a working tool in a study that will help children with Cystic Fibrosis. The app will be used to monitor the progress of the disease and to provide personalized advice to the patients. The app will be used to monitor the progress of the disease and to provide personalized advice to the patients. The app will be used to monitor the progress of the disease and to provide personalized advice to the patients."

**What will happen in the coming years?**  
"To test the MyCyFAPP app as a working tool in a study that will help children with Cystic Fibrosis. The app will be used to monitor the progress of the disease and to provide personalized advice to the patients. The app will be used to monitor the progress of the disease and to provide personalized advice to the patients. The app will be used to monitor the progress of the disease and to provide personalized advice to the patients."

The interview with Jessie Hulst about MyCyFAPP project was published in the monthly Magazine of Erasmus MC.

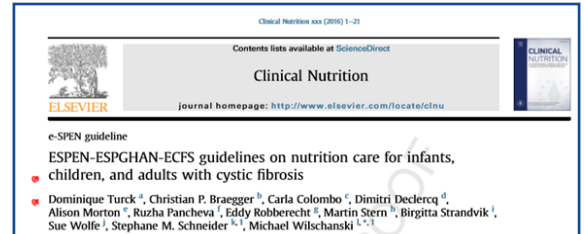
<http://www.erasmusmc.nl/medewerkers/?lang=en>

## OTHER NEWS

### ESPEN - ESPGHAN - ECFS GUIDELINES ON NUTRITION CARE FOR INFANTS, CHILDREN AND ADULTS WITH CF.

Achieving an optimal nutritional status in CF patients is important to maintain better pulmonary function and to prolong survival. These new guidelines update the ECFS guidelines delivered in 2002 and include a variety of topics

to address nutritional care in infants, children and adults. Statements were discussed, submitted by a panel of experts and then reviewed by ESPGHAN and ECFS and accepted in an online survey among ESPEN members. The most relevant updates include sodium, minerals and vitamins supplementation, specialized nutrition-related treatments such as essential fatty acid and probiotics. Attention has been paid to change induced in clinical problems of the disease that have emerged due to improved survival: bone disease, CF-related diabetes, liver disease, pregnancy.



## SOCIAL NETWORKS



ALL-NEW UPDATES ON MYCYFAPP PROGRESS ARE AT OUR SOCIAL NETWORKS. FOLLOW "MYCYFAPP"!!

AN INTERESTING INTERVIEW SERIES COMING SOON ON YOUTUBE. STAY TUNED!

COMING SOON:

#### ESPGHAN 49<sup>TH</sup> ANNUAL MEETING, 25<sup>TH</sup> - 28<sup>TH</sup> MAY 2016, ATHENS (GREECE):

- In vitro assessment of the influence of intestinal pH and enzyme/substrate ratio on fats digestion in CF patients. An e-poster will be displayed on Friday, 27 May 2016 at 13:45.
- J. Calvo will also present MyCyFAPP Project during the pancreas and liver working group session.

Presenter: Joaquim Calvo Lerna, HULAFE (Valencia, Spain).

<http://www.espgahancongress.org>

#### ECFS 39<sup>TH</sup> CONFERENCE, 8<sup>TH</sup> - 11<sup>TH</sup> JUNE 2016, BASEL (SWITZERLAND):

- Nutritional status, nutrients intake and enzymatic supplements in a European CF cohort: a cross-sectional overview. Presenter Joaquim Calvo Lerna, HULAFE (Valencia, Spain).
- Nutritional habits' characterisation in a European paediatric cystic fibrosis population: a multicentric survey. Presenter Tiago Martins, AIDFM (Lisbon, Portugal).

<https://www.ecfs.eu/conferences/basel2016>

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

27<sup>th</sup> - 29<sup>th</sup> June 2016 in Rotterdam (The Netherlands)



European Society for Paediatric Gastroenterology, Hepatology and Nutrition



European Cystic Fibrosis Society



MyCyFAPP



## THE MYCYFAPP CONSORTIUM:

We are a multidisciplinary research team, integrated by nutritionists/dietitians, 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.