



MYCYFAPP NEWS

N° 08 | October 2017 | www.mycyfapp.eu | [F](#) Mycyfapp | [T](#) MyCyFAPP

The co-developed APP MyCyFAPP is aimed at a personalised and accurate control and monitoring of the disease

The MyCyFAPP project aims at self-management of enzyme replacement in children with CF by means of a mobile application (APP) that allows for a personalized and accurate control and monitoring of pancreatic insufficiency.



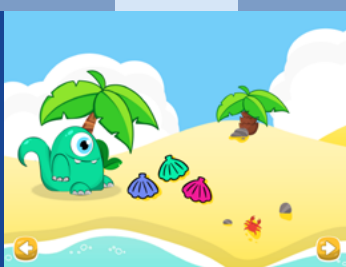
THE WAY UP TO THE CLINICAL TRIAL

We have been working along through these years to get a complete digital ecosystem to offer a solution for the challenge we are addressing: to develop a new model of calculation of the Pancreatic Enzyme Replacement Therapy.

The APP is ready to help patients to calculate their optimal enzyme dosage; the Web Professional Tool for doctors and nutritionists is set up so they can follow their patients' evolution. No less important, the game app is prepared to guide children in their learning process.

By the end of the year about 250 children of six Cystic Fibrosis units in Europe will join the clinical trial during six months to put the whole ecosystem to test.

Although the project has already been fruitful and many papers have been published, we hope to continue to offering solutions to improve the quality life of people. We do believe that joining technical expertise, clinical experience, research knowledge and the patients' view is the best way to find new solutions to daily issues.



1 INNOVA SALUTE 2017

The game has been rewarded with InnoSalute 2017 in the field of education and wellbeing

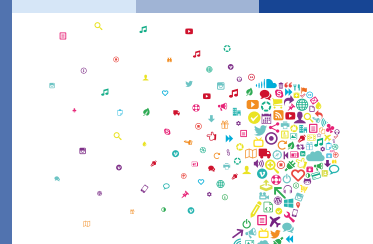


Journal of Cystic Fibrosis

The Official Journal of the European Cystic Fibrosis Society

2 COMMUNICATIONS ROOM

Last publication of MyCyFAPP. More to come in the following months.



3 NUTRITIONAL HANDBOOK

A useful guide for cystic fibrosis patients



GAME APP REWARDED WITH "INNOVA SALUTE 2017"

INNOVA SALUTE 2017 IS AN ITALIAN INITIATIVE LAUNCHED BY THE PUBLIC HEALTHCARE SYSTEM AND SUPPORTED BY THE PHARMACEUTICAL COMPANY TEVA, AIMED AT RECOGNIZING PROJECTS WHICH OFFER REAL SOLUTIONS WITH A HIGH IMPACT RESPECT TO THE GROWING HEALTH NEEDS. THIS YEAR, IT HAS REWARDED THE GAME APP AS THE BEST INNOVATOR IN THE CATEGORY "HEALTH AND WELL-BEING EDUCATION".

Lucia Pannese, CEO of Imaginary, the partner responsible for the development of the game APP, collected the Innova Salute 2017 award last September. As she explained, "it was a great honor to collect the award, fruit of years of hard work of a multidisciplinary team".

Taking care of the avatar

The avatar, main character of the game, is a nice monster who needs some basic care such as good nutrition, some sleep, hygiene habits, practicing sports... and players are responsible for the general wellbeing of the avatar. As the game progresses, the avatar status changes asking for rest or food. While playing with the games, children learn to understand their own needs, the importance of hydrating and practicing sports. In addition, they become familiar with the main macronutrients such as carbohydrates, protein, fats...

The reasons for the game

For the whole MyCyFAPP project Consortium was clear from the beginning that a smart way of involving children in the project needed to be found. While the main aim is to make understand what a healthy life implies and what are the nutrients of some food, the challenge was clear: to find a balance between learning and engagement.

Co-designing, not only with specialists, but with the target group of children themselves, has been the key to develop a funny and motivating game. Once the clinical trial starts, participating children will have the chance to play with the avatar.



Innova Salute Award



Game APP Avatar on its island

COMMUNICATIONS ROOM

Andrés Grau, AM (2017), "Behind MyCyFAPP Project: Correlating Inherent-to-Food Factors with Pancreatic Enzyme Requirements."
International Journal of Drug Research and Technology
Vol. 7 (6), E01

Calvo-Lerma, J. "Nutritional status, nutrient intake and use of enzyme supplements in paediatric patients with Cystic Fibrosis; a European multicentre study with reference to current guidelines."
Journal of Cystic Fibrosis. Volume 16, Issue 4, 2017, Jul;16(4):510-518

2ND INTERIM REVIEW

19TH SEPTEMBER BRUSSELS, BELGIUM

Last September representatives from all partners presented a comprehensive report updating the progress of the project to the official reviewers of the European Commission in Brussels. It was a great opportunity to assess the performance of our job. Reviewers appreciated the achievements up to now as well as the accurate compliance with the milestones and expected outcomes.



One of the sessions of the review

MY COOKING FAST CHALLENGE WINNER!

MORE THAN 30 RECIPES HAVE BEEN SUBMITTED TO THE CHALLENGE LAUNCHED LAST DECEMBER TO GET TASTY, HEALTHY AND HIGH-CALORIC RECIPES!

Since last December our facebook page followers have participated in My Cooking Fast: a challenge whose aim was to find recipes to help patients with cystic fibrosis to discover new ideas for their dishes. The rules were simple: posting a high-caloric recipe with pictures or videos and inviting two friends to join the challenge. The recipe with more Likes was "Salmone alle erbe" (salmon with herbs) from Roberto Brozzi. Congratulations to the chef!

Thanks to all participants who have taken part! Recipes will be available under the hashtag #mycookingfast.



One of the promotional videos of the challenge



NUTRITIONAL HANDBOOK: UNDERSTANDING CHILDREN WITH CYSTIC FIBROSIS

MYCYFAPP IS NOT ONLY AN APP AIMED TO CALCULATE THE OPTIMAL DOSES OF PANCREATIC ENZYMES REQUIRED FOR EACH MEAL: THE PROJECT EMBRACES A NEW MODEL OF HEALTHCARE WHERE PATIENTS HAVE AN ACTIVE ROLE. FOR THIS REASON, EDUCATIONAL RESOURCES ARE AN IMPORTANT PART OF THE PROJECT.

Some recent papers have confirmed that, when patients understand their treatment and symptoms, they improve their treatment results. The Nutritional Handbook is one of the resources created to provide end users with accurate, understandable and adapted informative content.

The Nutritional Recommendation Handbook is included in the APP and has been written with the aim of helping Cystic Fibrosis patients to increase their knowledge about their condition.

The handbook covers a wide range of aspects: from explaining the gastrointestinal implications of cystic fibrosis up to the psychological aspects of the illness, nutritional education information and tips for nutrition in special situations.

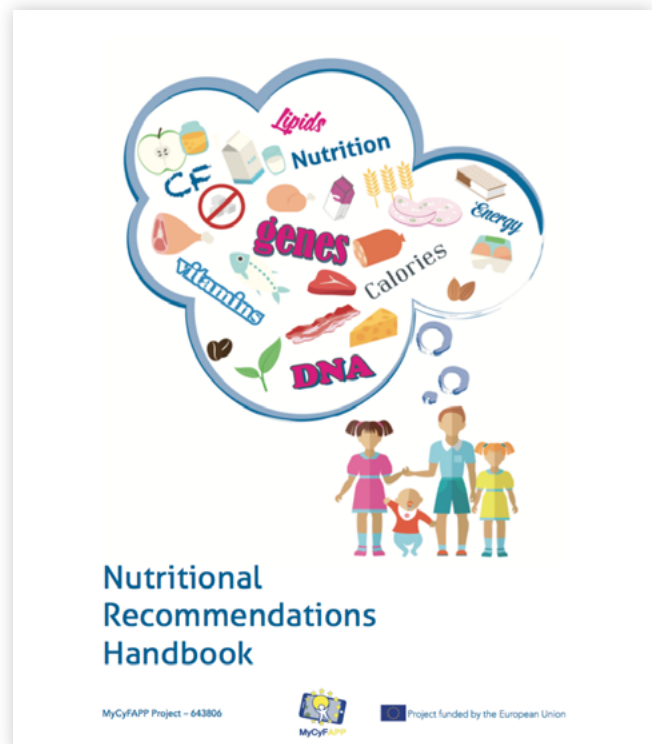
FREQUENTLY ASKED QUESTIONS

OUR WEBSITE HAS INCLUDED A NEW SECTION WITH THE AIM OF HELPING PATIENTS INVOLVED IN THE CLINICAL TRIAL TO UNDERSTAND HOW DOES THE APP WORK AND HOW USING IT CAN CONTRIBUTE TO IMPROVE THEIR GENERAL WELL-BEING.

As the project evolves, so does the website. For that reason, we have added a new section to solve the most common queries from patients involved in the clinical trial. The FAQ section includes a wide range of questions: from generic ones such as "What is the Pancreatic Enzyme Replacement Therapy" up to specific ones regarding data storage security or how the APP can help patients on the self-management of enzyme replacement therapy. We will carry on improving our website, updating information for health professionals and researchers without forgetting to provide accurate and high-quality content information for patients and their families.

As users may have some more queries, we will also be available to answer any question that may arise through an email account.

This section is only available in English but it will be translated to the languages from countries participating in the clinical trial.



Cover of the Nutritional Recommendations Handbook

COMING SOON

Spain, Italy, Wales, the USA... know where MyCyFAPP will be presented in the following months.

TU HOSPITAL INVESTIGA PARA TI (YOUR HOSPITAL INVESTIGATES FOR YOU). OCTOBER 21ST

HULAFE team has organised an informative session for Cystic Fibrosis association, patients and their families to explain them the availability of new drugs and MyCyFAPP project.

ABOUT PHARMA DIGITAL AWARDS. 26TH OCTOBER

Mycyfapp game is also participating in the About-Pharma Digital Awards competition: results will be announced on October 26th during the ceremony at gala dinner. Fingers crossed that our monster conquers this prize as well!

31ST AMERICAN CF CONFERENCE. NOVEMBER 3RD

CFE will present the Project in Indianapolis. This international meeting brings together physicians, nurses, research scientists, physical therapist, social workers and pharmacist.

NATIONAL CYSTIC FIBROSIS CONFERENCE. 10TH NOVEMBER

Joaquim Calvo from HULAFE will be presenting MyCyFAPP project in a workshop organised National Cystic Fibrosis Conference at the Cardiff and Vale University Health Board.

SPANISH NATIONAL CYSTIC FIBROSIS CONGRESS. 23RD-25TH NOVEMBER

Next November the Spanish National Cystic Fibrosis Congress will take place in Valencia. A great opportunity to share knowledge with health-care professionals and researchers. Some abstracts presenting pre-eliminary results of MyCyFAPP will be presented

STORIES BEHIND MYCYFAPP PROJECT

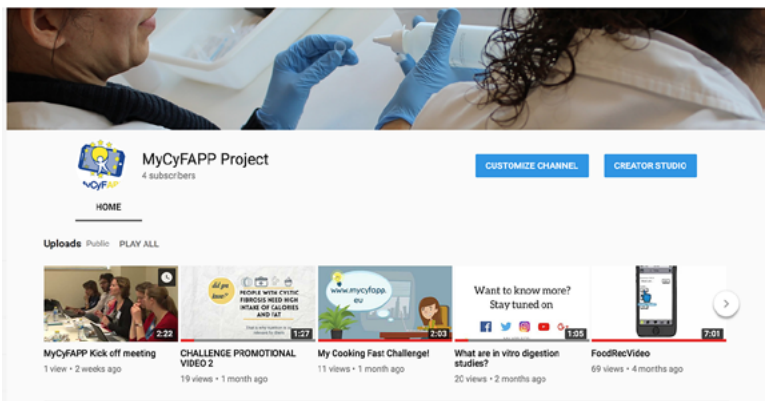
WE WANT TO APPROACH MYCYFAPP PROJECT TO PATIENTS, THEIR FAMILIES WHILE SHOWING TO THE WHOLE SOCIETY WHY INVESTING IN RESEARCH IS WORTHY, AND NECESSARY.

Sometimes laboratory work may seem far from everyday life.

However, for patients joining the clinical trial is obvious that research does improve their daily life. As Belén, a Spanish patient taking part in the project explains "is important to participate in this initiatives, they are a good opportunity to contribute the life improvement of many people".

Testimonies such as the Belén are a powerful tool to show why spending time on research is worthy. For this reason, in the following months we will be unveiling the faces behind MyCyFAPP project: parents, health-care professionals, doctors, technical partners will explain what MyCyFAPP is and how it contributes to science.

Subscribe to our YouTube channel and don't miss out any story!



VI PROGRESS MEETING

11TH-13TH DECEMBER 2017 LEUVEN, BELGIUM

Our partner UZ Leuven is getting everything ready for the next Progress Meeting which will take place on December 11th. We are all looking forward to working together along those three-day meeting.

CLICK AND FOLLOW US!



THE MYCYFAPP CONSORTIUM

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.



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