



MYCYFAPP NEWS

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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.



MESSAGE FROM THE COORDINATION TEAM

It has been almost two years now since we started this Project. A lot of new knowledge has been generated in the different disciplines involved and the MyCyFAPP consortium has become a very close team.

The results so far achieved include the characterisation of the nutritional habits in the paediatric population with Cystic Fibrosis in Europe, the current situation as compared to the New European Guidelines on Nutrition in CF, the lipid digestion characterization for a selection of foods and dishes, the development of the software prototypes for the APP and the professional web tool and games to support self-management and nutrition educational content addressed to patients and families.

Besides, the dissemination of our Project beyond the consortium has taken new initiatives: a series of interviews explaining the project and the challenge in the social networks.

Therefore we encourage patients associations and experts from very different areas, such as medical teams, food technologists and ICT developers to subscribe to our newsletter, which from now on will be released every three months.

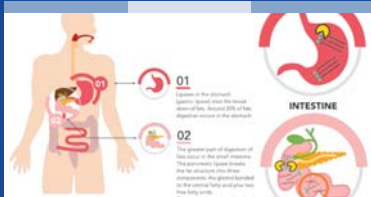
We take the opportunity to wish our readers all the best for the New Year 2017! Stay tuned to MyCyFAPP!

TRAINING WORKSHOP

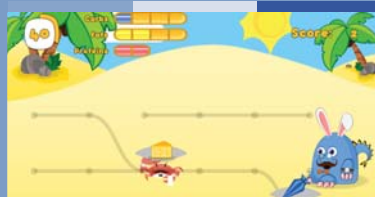
In the coming period of MyCyFAPP project we will start organizing a series of training sessions to instruct all the participants in the trial that will assess the effects of the use of the APP. The first training session will include a brief introduction to MyCyFAPP Project and a synthetic explanation of healthy eating & CF and PERT. The second training session will focus entirely on the use of the APP and will be more detailed. It will come in different versions adapted to the different audiences we want to reach:

- For medical teams we will explain how to use the professional web tool
- For patients the focus will be on how to use the games / APP
- For parents and caregivers we will focus on how to use the specific APP and interact with health professionals

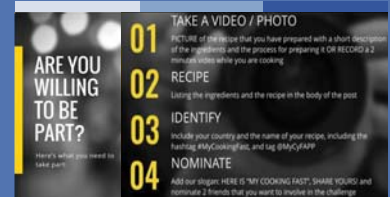
MyCyFAPP's communication committee will develop the content of these trainings together with the clinical and the technical partners.



2 MYCYFAPP NUTRITIONAL RECOMMENDATIONS HANDBOOK: HOT OFF THE PRESSES



3 NEW GAMES ARE LANDING ON THE ISLAND.



4 MYCYFAPP: ARE YOU WILLING TO BE PART?

THEORETICAL OPTIMAL DOSES OF ENZYMES: ON TRIAL!

Along this year, the in vitro digestion studies of food products have progressed as scheduled. We have already characterized the theoretical optimal dose of enzymes for a selection of meals, according to the gastrointestinal in vitro model. Patients enrolled in the pilot study of the project have already tested these doses for the same meals that were tested in the lab. Now it is time to find out the degree of accuracy of the prediction when moving to real persons. The analyses of fecal fat of the participants will reveal the correction factor that has to be applied to the predicted doses for an optimal fat digestion in patients. The second stage of the pilot study will start after the Christmas break: patients will repeat the test assuming the same meals but with personalised doses of enzymes according to the results obtained.

#MYCOOKINGFAST

All participants of MyCyFAPP project want to thank Chef Antonino Cannavacciuolo to have supported our cooking challenge: “#MYCOOKINGFAST”. Our team want to make MyCyFAPP fun so that people with CF have a wide range of dishes that help them to fulfil the nutritional goals. This cooking challenge can be the perfect occasion to bring out your cooking talent and share with us the best of your culinary talent. We are looking for tasty, delicious and filling recipes.



for more details read page 4

MYCYFAPP NUTRITIONAL RECOMMENDATIONS HANDBOOK: HOT OFF THE PRESSES

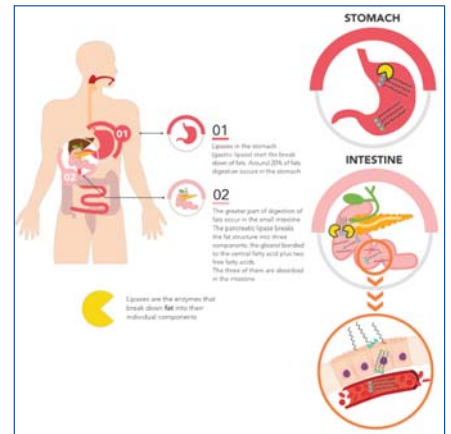
Last year, a European study on nutritional habits of children and adolescents with Cystic Fibrosis was carried out and allowed the characterization of dietary pattern and nutritional composition in the in CF patients from: Spain, Portugal, Italy, Belgium and The Netherlands.

The Nutritional Recommendation Handbook, written by MyCyFAPP researchers involved in this study, has been built up upon three principles:

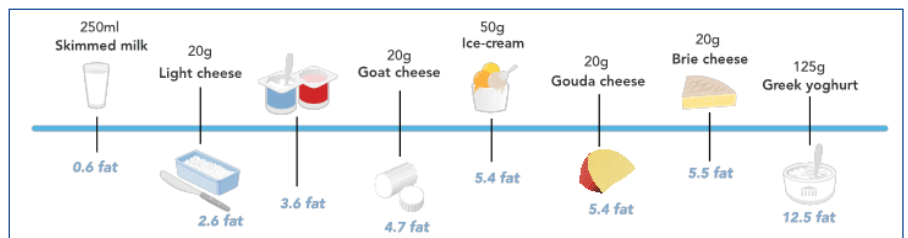
- Pursuing the most recent scientific evidence (New European Guidelines)
- Going beyond the current nutrition educational resources
- Addressing the current nutritional imbalances identified in the study

The Handbook is composed by four sections: About Cystic Fibrosis, Nutritional education, Lifestyle and Nutrition in special situations.

A total of 10 chapters embrace all the nutritional-related aspects that patients and their families should be aware of to support self-management, so contents are explained in a friendly and appealing style to empower and encourage them to understand what is in their hand.



how fats digestion occurs



how much fat is milk & dairy products

The book will be published soon, but more importantly, all the contents are being adapted so the APP can support them and users can access them anywhere, anytime. Overall, they conform one of the main feature of the APP.

START OF THE CLINICAL TRIAL: A PREVIEW

MyCyFAPP is nearly ready for use and we are preparing to test and evaluate it in the WP6 clinical trial. To evaluate the influence of the app on patient outcomes, we will ask patients to answer questions related to gastrointestinal problems. To start, we will use an existing general quality of life and gastrointestinal symptoms questionnaire (PEDSQoL-GI). However, this questionnaire was never used in patients with CF before, so it is unclear which questions will be most informative. Therefore, in the first part of the trial, we want to validate the PEDSQoL-GI in patients with CF and identify PEDSQoL-GI questions that can be used to evaluate MyCyFAPP in the second part of the trial.

For this purpose, patients and parents are asked to complete up to 3 questionnaires on two consecutive outpatient clinics with approximately 3 months in between.

1. Pediatric Quality of Life Inventory-Gastrointestinal Symptoms Module (PEDSQL-GI)
2. Cystic Fibrosis Questionnaire-Revised (CFQ-R)
3. Visual Analogue Scale (VAS).

THE MOST CONSUMED FOOD PRODUCTS BY CHILDREN WITH CF IN EUROPE

The European study on nutritional habits in Cystic Fibrosis has also pictured how the intake of different food groups is among the study populations. Are you feeling curious to learn more?

MILK & DAIRY PRODUCTS:

In Belgium, Spain and The Netherlands, whole-fat milk is more consumed, whereas in Portugal and Italy the semi-skimmed milk has a higher frequency of intake.

There are also differences in the type of cheese consumed:

-  Gouda in Belgium and The Netherlands
-  Parmigiano in Italy
-  Edam in Portugal and Spain


MEAT:

In all the countries, chicken breast is the most consumed meat, followed by pork and beef.




FISH:


white fish

-  Hake is the most consumed in Spain and Italy
- Cod is the most consumed in Belgium, Portugal and The Netherlands

blue fish

salmon is the most consumed in all the countries 

FATTY FRUIT:

In Portugal the children do not consume fatty fruit. 

The avocado is the fatty fruit most consumed in Belgium, Spain and The Netherlands whereas the olives in Italy.



SWEETS AND SAVOURY SNACKS

Belgium, The Netherlands and Spain are the countries with the highest consumption of chocolate and sweets and Italy the country with the highest consumption of different types of biscuits.



FATS

There are important differences in the type of fats used for cooking.

-  Belgium and The Netherlands use butter
-  Italy, Portugal and Spain use olive oil

BEVERAGES: JUICES AND SOFT DRINKS

Belgium and The Netherlands are the countries with the highest consumption of these products, followed by Spain, Portugal and Italy.

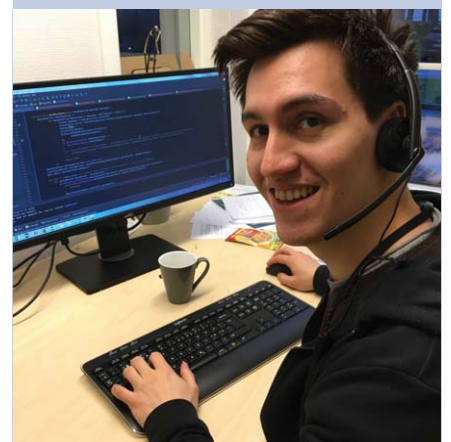


READY FOR THE MID-TERM EVALUATION OF THE SELF-MANAGEMENT APP?

The users were involved in gathering of requirements for the self-management app, in the app co-design and in usability tests of the initial prototypes. It is now time to get their feedback on a beta version of the app! Then we will refine and extend the app before the clinical trial starts next summer.

The evaluation will be conducted in the Netherlands and in Spain. Teenagers and young adults with CF, as well as parents of children with CF, will participate. The beta version supports basic functionality for food recording, diary keeping and educational content. The evaluation focuses on usability and usefulness from a functional perspective, not from a health perspective. It consists of two steps: We will first meet participants for a one-hour test and observe their reactions while they try the app for the first time; then participants will use the app during one week and record their experience. We will interview participants after this week.

Special thanks to the developers who work hard back the scene to provide a well-functioning, stable and easy-to-use beta version ready for the mid-term evaluation!



Peter is one of the key developers of the self-management app

NEW GAMES ARE LANDING ON THE ISLAND.

The fantasy island, where our hero lives, is enriched by two new games: the Crab Restaurant and the Cave. Now, the avatar can leave its house, take a walk by the seaside, meet a little crab waiter and play with it to choose the right foods to eat!

To stay hydrated, the avatar must visit the deep, dark cave and fill a container that is holding in its hands by trying to collect each drop of water as it falls from the stalactites on the ceiling. By playing these new games, children affected by Cystic Fibrosis can increase their awareness of the importance of nutrition and hydration in order to adopt healthier behaviours in real life.

UPV-ITACA IS JOINING MYCYFAPP PROJECT!



Their main role will be in WP5 and WP8 as leaders, where they will co-develop the mobile app and web tool together with Sintef and guide the exploitation activities. They will be actively participating in WP4 and WP6, for helping in the evaluation process, especially in tasks related to the mobile app and will also give a small contribution in dissemination.

UPV-ITACA is, as we know, SABIEN (Health and Wellbeing Technologies) R&D&i Area of the Institute for the Application of Advanced Information and Communication Technologies (ITACA), inside the Universitat Politècnica de València (UPV).

UPVLC-SABIEN has been participating in more than 40 European and National projects since 1998, having an extensive expertise in the application of ICT to the social and healthcare systems, in Ambient Assisted Living technologies (AAL), and Internet of Things (IoT) and also in reengineering and evaluation, validation and exploitation of social and health care processes and solutions in real environments.

Projects related to chronic patients' management, and ICT in nutrition and fitness that are worth to mention are ACTIVATE (A platform on Cloud for families to care for dependent people to help them in better manage day-to-day care), FLASHDIET (MOOC to create awareness and tools for clinicians about healthy nutrition www.flashdietproject.eu), NUTRIPRO (<http://www.projectnutripro.eu/project-description/> Screening programme of the nutritional status of older people using ICT, mainly in residences) or HEARTWAYS (solution for supporting cardiac patients in rehabilitation outside a medicalized centre with the aid of wearable sensors and intelligent algorithms that personalize the management and the follow-up)

SABIEN website: <http://www.sabien.upv.es>

SABIEN publications: <https://scholar.google.com/citations?user=2UXnQWkAAAAJ&hl=en>

SABIEN YouTube Channel: <https://www.youtube.com/user/tecnosaludybienestar>

SABIEN presentations: <http://www.slideshare.net/vtraver>

#MYCOOKINGFAST

ARE YOU WILLING TO BE PART?

Here's what you need to take part:

- 01 TAKE A VIDEO / PHOTO
PICTURE of the recipe that you have prepared with a short description of the ingredients and the process for preparing it OR RECORD a 2 minutes video while you are cooking
- 02 RECIPE
Listing the ingredients and the recipe in the body of the post
- 03 IDENTIFY
Include your country and the name of your recipe, including the hashtag #MyCookingFast, and tag @MyCyFAPP
- 04 NOMINATE
Add our slogan: HERE IS "MY COOKING FAST", SHARE YOURS! and nominate 2 friends that you want to involve in the challenge

SOCIAL NETWORKS:



TO STAY UP TO DATE FOLLOW US ON OUR SOCIAL NETWORK PAGES: "MYCYFAPP".

COMING SOON

MYCYFAPP 4TH PROGRESS MEETING
16TH - 18TH JANUARY 2017 IN VALENCIA (SPAIN)



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.