

ECORN-CF: www.ecorn-cf.eu

Editorial, by Thomas Wagner

Wanted	1
ECORN-CF- a short retrospective	2
Answers to the questions we asked	4



WANTED

Financial Support for ECORN-CF
From

YOU!

Mukoviszidose e.V., the German CF patient organization, has committed a fantastic 25.000 € for the continuation of the ECORN-CF quality assurance work. We are very grateful for this and very much hope that all patient organizations in Europe will contribute to the best of their possibilities as well. So it is up to you to convince your patient organization to keep helping ECORN-CF promote quality of expert advice across Europe and make such advice easily accessible in all member states.

The Future of ECORN-CF

Like with most EU funded projects, the happy times of grant money given for the planning, implementation, and running of cross-border activities end after a few years. For ECORN-CF the funding from DG SANCO – thanks again to them and to the Executive Agency for Health and Consumers – ends in April 2010. Since we are in the lucky position to have extra financial support from the Christiane Herzog Stiftung, a foundation of the former German President's wife, ECORN-CF will not have to end all of a sudden. Therefore, we all have to decide what the future scope of ECORN-CF shall be, whether we think it should be continued, and who is going to pay for it.

Do we need ECORN-CF?

The German CF patient organization has unanimously voted “yes”; even in a country with a large number of CF centres the patients think it helps a lot to have a group of experts willing to answer (anonymous) patient questions to the best of their expertise. The large number of questions coming from German patients and other lay persons like family members underscores this very clearly. So we dare to extrapolate this to other countries (language zones), not only but also to those countries where the availability of expertise is not so well or evenly developed. This does not help directly with the availability of certain drugs or treatments, but it certainly helps building pressure to eventually attain the goal of the European treaty: equal rights and opportunities across all member states.

Which are the most important elements of ECORN-CF?

The giving of advice by the local experts has always been – even during the period of EU funding – a matter of good-will; the experts have provided the answers at no charge and most of them have even translated the questions and answers so they can be put in the Central (European) Archive in English. This has been the crucial first step, but the pivotal strength of the collaboration certainly lies in the willingness to participate in a cross-border quality assurance program. I am convinced that every single expert has learnt a lot from being a part of that system. While we expect the local experts to continue their efforts at no charge, we need some financial support to keep the quality assurance program running.

Who might be willing to pay for ECORN-CF?

When designing what became ECORN-CF, we had in mind to provide the expert advice to patients and to the care team members. The reality has been much on the side of the patients/lay persons: more than 90% of all questions came from them. This – together with the positive evaluation given by the German patients – makes us hope that the other patient organizations see it in a similar way: it is a valuable service for patients. If all European patient organizations join forces in contributing to the financial support of ECORN-CF this should easily sustain this program. This explains why we put Uncle Sam up front asking for your contribution. During the next few months we will get in touch with all European patient organizations to see whether they consider ECORN-CF worth supporting.

We will see!

For the coordination team of ECORN-CF
Thomas Wagner, Frankfurt

ECORN-CF- a short retrospective

When ECORN-CF started 3 years ago the goals were clear: to make a website available for lay people with an interest in CF, and for CF-care teams, a kind of helpdesk where every one within the EU could turn to with all kinds of questions related to CF. Three years ago we embarked with this goal on the horizon and hoped that favourable winds would bring us there. Now we have to end our journey and we ask ourselves if we reached the set goals.

After the official first meeting in August 2007 in Frankfurt a good speed was made: thanks to the efforts of the German webmaster together with the tireless Annette the first three websites, namely the British, Czech and German, were launched in October

2007. Within a year the Romanian, the Lithuanian, the Belgian/Dutch, the Polish and Swedish websites were launched. In the preceding months test questions had been mailed to every-one and the given answers were discussed during the meeting in Frankfurt. Official guidelines and consensus documents had been compiled in a document to be used to provide well-balanced answers. During the 2nd Quality Round Table in April 2008 in Prague we discussed a number of questions asked in the ECORN-CF expert advices and which had been difficult to answer. Despite all the available documents for many questions there was no answer in the guidelines. Often the cause is that CF-patients and their families live their lives as normal as possible with all the constraints of the disease but still as normal as possible, and then questions arise about a journey the family likes to make to Spain or to Thailand or about the pet in their home or about safe ventilation systems. For very few of those ordinary daily life questions answers can be found in the current CF-guidelines.

So another goal was set: to write a document with all the questions and answers about travelling with CF. This document was extensively discussed during the next Quality Round Tables in Frankfurt and in Prague and will be published very soon. I feel this might become a must-have travel document for every CF-patient and family and at least as important as the usual one.

Since March 2009 there is also a Greek website. We expect that a French website will be launched in the middle of this year.

It is a good thing to offer a service like providing expert advice on the net but the best service cannot be used if the "customers" are not aware of it. We therefore drafted a special leaflet that was distributed among the participants of the 2008 ECFS conference. After that we also provided a template that after translation in the own language offered each ECORN-partner the possibility to inform their CF-centers, or to publish information about ECORN-CF in the national CF-newsletters, or to put information about ECORN-CF in waiting rooms of CF-centers. Using this information in a short article about ECORN-CF in the Dutch CF-newsletter in the summer of 2008, led to a considerable increase of questions for the website in Dutch language.

Once questions are asked and the users are satisfied with the answers then the most important matter is to keep the quality as good as possible. Another goal of our project journey was to learn from each other. The Quality Round Tables served at the same time as a forum and an exchange platform which led to further improvement of the answers. Since October 2009 a "Question of the Month" is mailed to all participants of ECORN-CF and other interested people. The number of Question-Answer pairs (QA's) as published on the Central Archive is ever increasing. At this moment 701 QA's can be found in the quality checked Central English Archive on the



Key words on Apr 27, 2010 from the Central Archive of ECORN-CF

ABPA Aspergillus accompanying diseases air-improving devices allergy animals pets antibiotic therapy complementary medicine diabetes diagnostics drugs side effects drugs under development genetic therapy general aspects genetics health care hepatobiliary disease hygiene i.v.: lines inhalation lung microbiology miscellaneous MRSA nutrition and GI problems oxygen supplementation therapy physiotherapy Pseudomonas aeruginosa psychosocial public facilities reproduction social law sport swine flu novel influenza transplantation travelling vaccination

ECORN-CF website and many topics are covered. I advise to find this out by going to the website and have a look at all the questions that have been asked already: [http: www.ecorn-cf.eu](http://www.ecorn-cf.eu)

Some language zone websites were more successful than others, the German website has a topic list of 483 questions, but the Polish and the Romanian show about 25 questions. One can think of many reasons that cause this difference, but then we would need another ECORN-CF journey to find out.

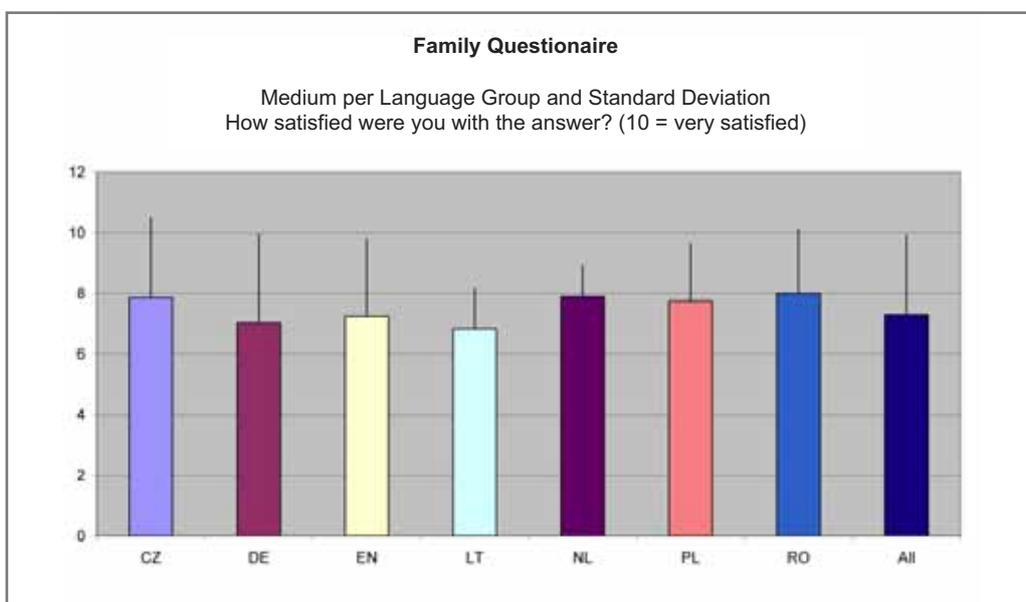
Answers to the questions we asked

In the second newsletter we published an example of the questionnaires that were sent to patients or families that asked questions on the ECORN-CF.EU website. These questionnaires were meant to get insight into CF related problems, but one of the items in the questionnaire was a question about the answer the family or the patient got from ECORN-CF. To improve the website and its usefulness for the users (and as a result strengthen its popularity) we wanted to know whether the questioners were satisfied or not with the answer(s) they got. We asked therefore to give a score from 1 (not at all) to 10 (very satisfied) on the question "Were you satisfied with the answer to your question?". Only families and patients who asked their questions after they registered on the website received a questionnaire.

The first e-mail requesting to fill in the questionnaire was sent on December 12, 2008 to 396 e-mail addresses. We received back 88 family questionnaires and 45 patient questionnaires; this leads to a return rate of 33,6%.

The second e-mail requesting to fill in the questionnaire was sent on December 2, 2009 to 654 e-mail addresses. We received back: 73 family questionnaires and 42 patient questionnaires. Return rate: 17,6%.

I wondered whether actions were undertaken when the satisfaction-score was less than 6, but to my regret actions were not undertaken systematically, only sporadically. Maybe this needs some attention when ECORN-CF will be continued! However, luckily most people that filled out the questionnaires were quite happy with the answers they got, although the response rate to the questionnaires was obviously too low for a reliable result. The Table and the Figure shows the mean scores that were given and the standard deviation. From some countries the number of returned questionnaires seems to be very low.



**Family Questionnaire:
How satisfied were you with the answer?**

Country, n	Mean (10 = very satisfied)	Standard deviation
CZ, 21	7,9	2,7
DE, 82	7,0	2,9
EN, 17	7,2	2,6
LT, 6	6,8	1,3
NL/BE, 9	7,9	1,1
PL, 4	7,8	1,9
RO, 5	8,0	2,1
Total, 144	7,3	2,6

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