



**ECORN-CF: [www.ecorn-cf.eu](http://www.ecorn-cf.eu)**

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Associated partners and collaborating organizations	2	It is with mixed feelings that I look at what has become so far of the idea of more than a year ago: European Centres of Reference Network for Cystic Fibrosis. The ideas were there: build a network of communication for CF patients and relatives, give advice on the net to them and to members of the CF Care team; share the experience and profit from the experience of others; learn from the best.
Who is who in ECORN-CF	3-5	I want to show you what I mean: when we first started the German CF Expert Advice as a service of the German CF patient organisation (Mukoviszidose e.V.) we had done so in the simple and somewhat naïve expectation we as an experienced CF care team would be able to give this advice. It did not take long before we had to ask some real experts on special topics for their help – and every one we asked was willing to help, not one of the most renowned experts did ever refuse to share their knowledge with us and with those seeking advice. And we - the self proclaimed experts - did learn a lot. The message was: no matter how much experience you may have, there will always be someone with whom it is worthwhile to exchange your thoughts, and there will probably be more who would be grateful to hear what they or you think about this topic.
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Consensus reports	7	There is an enormous wealth within this kind of expert advice: First there is the expert opinion, very often not to be found in any written text - book or paper - and of course there is a special and unsurpassed value coming from the one who asks: these are the true questions, these are the problems that have not been solved, that really matter.
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Contacts	10	How can we achieve to have all this in all of the European member states? Well, we try to make available in every member state language for every patient or care team member the best possible expert advice. And by doing this, we try to make every partner learn from the best, hopefully leading every one of our partners to the highest European level of expertise. And what happens, if there is not just one opinion, not one consensus on what has to be considered to be the best possible answer to the question? Well, then we will try to contribute to such a consensus – e.g. by forwarding the question to the European Cystic Fibrosis Society. The reason we think this is important lies in the wealth of what the patients and other questioners provide us with: we will have the questions, even if we cannot yet give the answers.
Forthcoming events	10	So the feelings somehow resemble those I had when my oldest son after having left home for a year of high school in the states wrote in a letter that he had met a nice photographer who wanted to do a shooting with him – and me the father had many fears of what might happen – this was in the years of airmail letters taking a minimum of five days from the United States to Germany – so someone said to me then: ‘what you did not teach him by now, he must learn himself, and by the way: he will have learnt before you can get him on the phone.’  Yes, there is a time when you have to trust those you have brought some part of the way that they will do the rest themselves – I hope and I am confident that ECORN-CF will make it.  With my best wishes Thomas Wagner

## A short introduction to ECORN-CF

### What does ECORN-CF mean?

The acronym ECORN-CF stands for **E**uropean **C**entres of **R**eference **N**etwork for **C**ystic **F**ibrosis. The main task of this network will be to offer expert advice about CF via internet in the mother language to lay people and experts seeking information about CF. If successful, this model can serve as a platform to start similar internet-based expert-services for rare diseases.

### What led to the development of ECORN-CF?

The idea to build an internet based expert advice system for both CF-patients, their parents, partners as well as their caregivers arose from the earlier started initiative in Germany ([www.muko.info](http://www.muko.info)). The model used in Germany served as an example for the development of the European network. In short it will provide the opportunity for patients and CF-caregivers in (currently) 9 EU-countries to ask questions related to CF via internet in their mother language.

The goal of ECORN-CF is to answer these questions via internet in the mother language within approximately 3

working days. All questions and answers are available for users of the website of ECORN-CF.

Additionally, for professionals of the CF care team a special expert advice has been set up. These questions and answers are only available for CF care team members.

The English, Czech and German expert advice started on 1st October 2007. See [www.ecorn-cf.eu](http://www.ecorn-cf.eu)

### What else can be achieved by ECORN-CF?

By expanding the internet expert advice throughout Europe it probably will lead to extended use of the European CF guidelines within the participating countries; it will elicit questions for which the currently available guidelines cannot provide answers and therefore will show the areas where new guidelines should be developed; and, it will help benchmarking between CF-centres throughout the EU.

## Which are the 9 associated partner countries in this project?

Representatives of Belgium, Czech Republic, Germany, Netherlands, United Kingdom, Lithuania, Poland, Romania and Sweden are actively involved in the development of the ECORN-network, indicated on the map of Europe in light blue

Collaborating organizations are located in Cyprus, Denmark, Finland, France, Greece, Italy, Hungary, Norway, Portugal, Slovakia, Spain, Switzerland and Turkey, indicated in brown

Language is important in ECORN-CF!

At present 8 language zones are actively involved—Czech, Dutch, English, German, Polish, Lithuanian, Romanian and Swedish—but there are potentially 20 language zones.



## Who is who in ECORN-CF

The tasks within ECORN-CF are distributed over 7 workpackages; each workpackage has a leader and a deputy.

### *Workpackage 1 Coordination of the project*

Leader: Thomas Wagner, professor in Pulmonary Medicine, Frankfurt, Germany  
Deputy: Tim Hirche, physician, University Hospital, Frankfurt, Germany

Tasks:

- monitoring of all activities
- administration
- organising different activities
- checking if goals are fulfilled
- monitoring time schedule



### *Workpackage 2 Dissemination of the results*

Leader: Jeannette E. Dankert-Roelse, pediatric pulmonologist, Atrium medisch centrum, Heerlen, Netherlands  
Deputy: Thomas Wagner, professor in Pulmonary Medicine, Frankfurt, Germany

Tasks:

- Obtaining input from all associated partners for the quarterly newsletter
- Putting together and distributing the newsletter



### *Workpackage 3 Evaluation of the project*

Leader: Thomas Wagner, professor in Pulmonary Medicine, Frankfurt, Germany  
Deputy: Tim Hirche, physician, University Hospital, Frankfurt, Germany

Tasks:

- Complete evaluation of the project

### *Workpackage 4 Expert advice to CF-patients and other lay people*

Leader: Helge Hebestreit, Würzburg, professor, pediatrician, specialized in pulmonology and sports medicine  
Deputy: Thomas Wagner, professor in Pulmonary Medicine, Frankfurt, Germany

Tasks (in cooperation with the associated partners of ECORN-CF)

- to build a team of experts who are available for evaluating and correcting – if necessary - advice that was given on the net to patients and other lay people. This evaluation will be done for questions and answers from all the local expert teams in all the member states.
- select and disseminate the appropriate guidelines and consensus papers (together with the leader of workpackage 5)



### *Workpackage 5 Experts' advice to members of the CF care team*

Leader: Stuart Elborn, professor in Respiratory Medicine, Belfast, UK  
Deputy: Thomas Wagner, professor in Pulmonary Medicine, Frankfurt, Germany

Tasks (in cooperation with the associated partners of ECORN-CF)

- to build a team of experts who are available for evaluating and correcting – if necessary - advice that was given on the net to other members of the CF care team i.e. doctors, nurses etc. This evaluation will be done for questions and answers from all the local expert teams in all the member states.



## Who is who in ECORN-CF– continued

- select and disseminate the appropriate guidelines and consensus papers (together with the leader of workpackage 4)

### *Workpackage 6 Quality assurance program*



Leader: Jitka Brazova, pediatrician, University Hospital Motol, Charles University Prague, Czech Republic

Deputy: Thomas Wagner, professor in Pulmonary Medicine, Frankfurt, Germany

Tasks: (together with the other associated partners in ECORN-CF)

- Organizing quality round tables twice a year for all experts involved in the process to reach consensus about diagnostic and therapeutic issues
- Managing the quality improvement program
- Selecting areas where guidelines are missing

### *Workpackage 7 Evaluation of the impact of the program on quality of care and implementation of the guidelines*

Leader: Thomas Wagner, professor in Pulmonary Medicine, Frankfurt, Germany

Deputy: Ernst Rietschel, Director CF-centre Köln, Germany

Tasks:

- describing the quality of the expert advice network and the quality of the advice given
- evaluating the adherence of experts to the European consensus recommendations
- reporting on the results of patient questionnaires

## Who is who – partners in WP 4, 5, 6 & 7

***Karleen de Rijke***, president of CF-Europe, Bonn, Germany

Task: to promote the idea of ECORN-CF throughout Europe, especially to the EU member states and language zones that are not part of ECORN-CF

***Christiane de Boeck***, pediatric pulmonologist, KU Leuven, Leuven, Belgium

Task: to link ECORN-CF to the ECFS and EuroCare-CF

***Birgit Dembski***, representative of the patient organisation Mukoviszidose e.V.

Task: to develop a patient questionnaire to evaluate the project

***Gerd Döring***, medical microbiologist, Tübingen, Germany

Task: to evaluate all questions relating to infection control guidelines and microbiology

***Hans Kollberg***, medical advisor, Ova Production AB, Vittinge, Sweden

Task: local moderator of setting up the local expert advice team and getting the Swedish patient organization to be part of ECORN

**Burkhard Tümmler**, Medical University Hannover, Germany

Tasks: contribution to the project quality management plan  
expert in German expert advice team

**Ioan Popa**, Victor Babes University, Timisoara, Romania

Tasks: local moderator of setting up the local expert advice team for Romania and getting the Romanian patient organization to be part of ECORN-CF

**Wojciech Cichy**, Academia Medyczna, Poznan, Poland

Task: local moderator of setting up the local expert advice team for Poland and getting the Polish patient organization to be part of ECORN-CF

**Vaidutis Kučinskis**, Dept of Human and Medical Genetics, Vilnius University, Vilnius, Lithuania

Task: local moderator of setting up the local expert advice team for Lithuania and getting the CF patient organizations to be part of ECORN-CF

## The Quality Assurance Program

Frankfurt Round Table WP 6 Summary - Quality Assurance Measures

by WP leader: Jitka Brazova (jitka.brazova@centrum.cz)

*What is quality management according to Wikipedia:*

“Quality management is a method for ensuring that all the activities necessary to design, develop and implement a product or service are effective and efficient with respect to the system and its performance.”

And this is what we want to do in ECORN-CF WP6: the project was already planned, we will continue in planning, we will work very actively, we will cooperate with other ECORN-CF workpackages and other CF organisations in Europe, we will review our results very carefully and we will improve our work according to achieved results (see picture).

Two main goals of WP 6 are: Establish a European cross border Quality assurance program and Implementation of European consensus.



WP 6 will organize quality round table meetings for all experts involved in the process twice a year. We will very closely cooperate with CF relevant organisations (ECFS; CF-Europe, EuroCare-CF etc.), and all participants interested in the quality of care of CF patients (open access) to reach consensus on diagnostic and therapeutic measures. In Frankfurt we agreed on rather few indicators of quality of care which are covered by an unequivocal statement of the European Consensus (Kerem E, Conway S, Elborn S, Heijerman H. Standards of care for patients with cystic fibrosis: a European consensus. *J Cyst Fibros* 2005; 4(1):7-26). These will be compulsory for every expert involved in ECORN-CF. They will be also published on ECORN-CF website so every expert can read these any time. The implementation and evaluation of adherence to European guidelines will be assessed by analysis of the content of the answers, by sham questions, and by use of a patient questionnaire. We started the work on patient questionnaire in Frankfurt and we decided to cooperate with EuroCare CF project and partly use the already existing questionnaire. *continued at page 8*

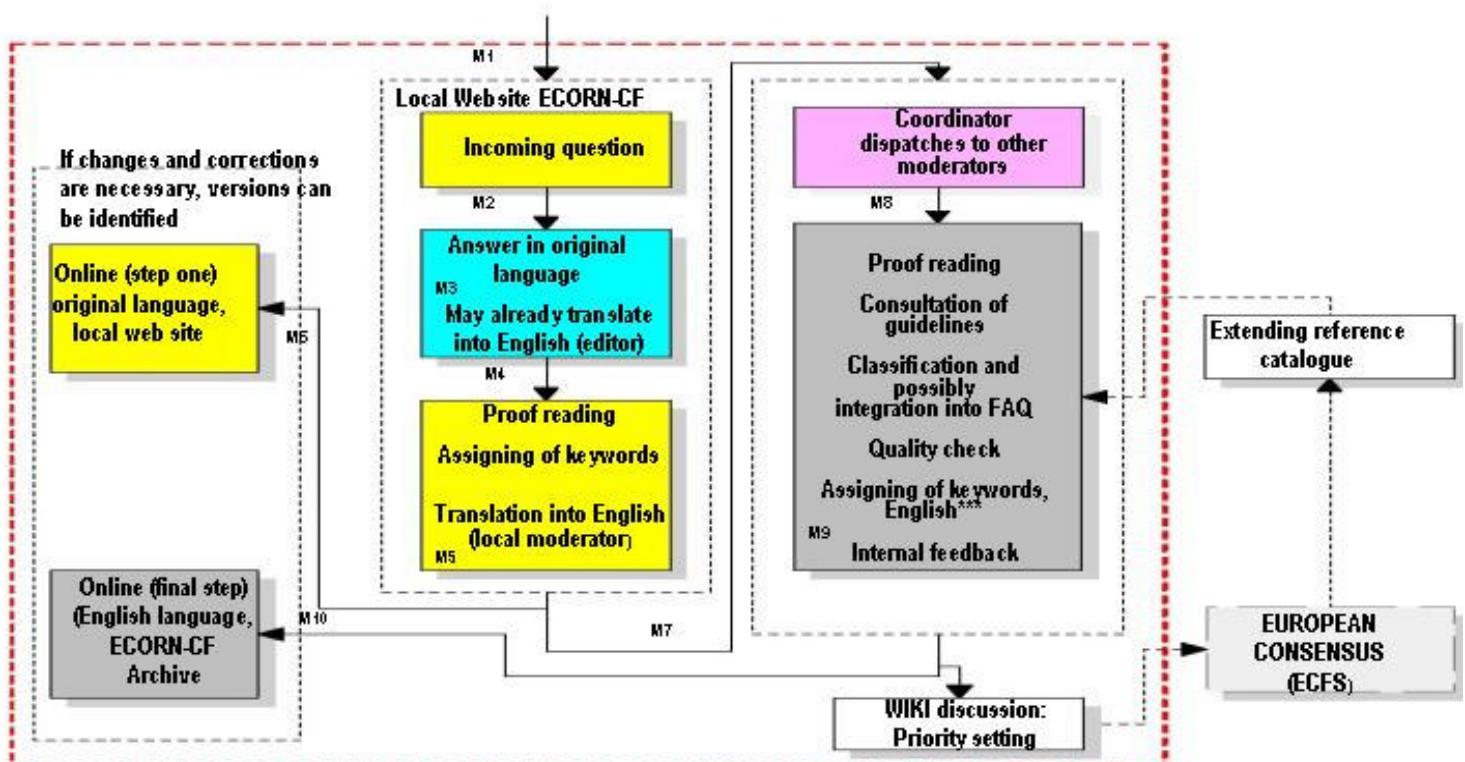
## The inside machinery of Questions and Answers

The nucleus-activities of ECORN, or maybe even better the mitochondrial activities, are shown in the schematic diagram, pictured here under. This diagram is very important because it shows how every question gets an answer in the mother as well as the English language in due time. Moreover, all questions and answers will be stored in an accessible archive. And, last but not least, it will lead to white spots on our map of knowledge of the diagnosis and treatment of CF and CF-associated diseases.

Which is the way a question travels through this answering-machine?

### Within the local website

After a question is posted at the local website (the question will only be published by the moderator when the answer is ready), the moderator will get an e-mail notification. The moderator will send this question to his local expert who is called „editor“ in the language of the system. The editor will also be notified by e-mail. He/she will answer the question in the original language, also start or do the translation into English, if possible and then send the question within the system back to the moderator. The moderator will proof read the answer, assign keywords and – if not done by the editor – translate the question and answer. Even if the translation is not ready, the question/answer in the original language can already be published in the local expert advice. If the questioner is not anonymous he/she gets an e-mail notification. While the questions published on the local website can be read by everybody, the answers can only be read when logged in.



### **Within the English archive**

Once the English translation of a question/answer pair is ready, the moderator can send it to the so called „coordinator“ of the archive for approval. An e-mail will be sent to the coordinator to inform that a question and answer are waiting for approval / quality check. The question/answer will be forwarded to a moderator of another language zone who is called in the role „proof editor“. The proof editor will be notified by e-mail and then has to proof read, check the consultation of guidelines, do a quality check and assign keywords. After that he/she can either publish the question/answer in the archive or send it back to the coordinator who can publish them.

## **Consensus reports published by the ECFS to be used when answering questions**

### **ECFS: Consensus Reports on Issues Associated with Clinical Aspects in Cystic Fibrosis**

**Döring G, Conway SP, Heijerman HGM, Hodson ME, Høiby N, Smyth A, Tow DJ** for the Consensus Committee.  
Antibiotic therapy against *Pseudomonas aeruginosa* in cystic fibrosis: a European consensus.  
*European Respiratory Journal* 2000; 16: 749-767

**Sinaasappel M, Stern M, Littlewood J, Wolfe S, Steinkamp G, Heijerman HGM, Roberecht E, Döring G**  
Nutrition in patients with cystic fibrosis: a European consensus  
*Journal of Cystic Fibrosis* 2002; 1: 51-75

**Döring G, Høiby N** for the Consensus Study Group  
Early intervention and prevention of lung disease in cystic fibrosis: a European consensus.  
*Journal of Cystic Fibrosis* 2004; 3: 67-91

**Kerem E, Conway S, Elborn S, Heijerman H** for the Consensus Committee  
Standards of care for patients with cystic fibrosis: A European consensus  
*Journal of Cystic Fibrosis* 2005; 4: 7-26

**Malfroot A, Adam G, Ciofu O, Döring G, Knoop C, Lang AB, Van Damme P, Dab I, Bush A,** for the ECFS Vaccination Group  
Immunisation in the current management of cystic fibrosis patients  
*Journal of Cystic Fibrosis* 2005; 4: 77-87 (no hard copy in this booklet)

**Doring G, Elborn JS, Johannesson M, de Jonge H, Griese M, Smyth A, Heijerman H;** Consensus Study Group  
Clinical trials in cystic fibrosis  
*Journal of Cystic Fibrosis* 2007 Apr; 6(2): 85-99

**Quality assurance program by Jitka Brazova, continued from page 5**

The next Quality Round Table (QRT) will be in Prague 22.-24.4.2008. We will discuss the most interesting and difficult questions already asked at the ECORN-CF website to reassure or redefine quality standards or to contribute to consensus meetings. We will go through all hot topics in ECORN-CF project. We will collect and prepare data for implementing of European guidelines. During this 2<sup>nd</sup> QRT all participants will get the possibility to visit the CF Centre at University Hospital Motol.

The second Quality Round Table will be held in Prague from April 22 – April 24, 2008





## From the minutes of the first Quality Round Table, August 22-23, 2007, Frankfurt

The meeting was considered more like a kick-off meeting rather than a quality round table since the expert advice was not online yet.

Although the meeting was scheduled at short notice many project partners made it possible to join. And it was worth while since the meeting was very fruitful and has brought the project forward.

The attendees were: Judy Bradley on behalf of Stuart Elborn (UK), Jitka Brazova (CZ), Daniela d'Alquen on behalf of Helge Hebestreit (DE – Würzburg), Birgit Dembski (DE – Bonn), Karleen de Rijcke (BE), Tim Hirche (DE – Frankfurt), Hans Kollberg (SE), Vaidutis Kučinskis (LT), Annette Pfalz (DE – Frankfurt), Burkhard Tümmeler (DE – Hannover), Silke van Koningsbruggen on behalf of Ernst Rietschel (DE – Cologne), Thomas O.F. Wagner (DE – Frankfurt).

Please find some outcomes of the meeting below:

The feedback to the questions sent to everybody before the meeting was discussed. It is important to know how the scoring system works although not everyone will use it. Answers will be scored on content quality (3 items) and formal quality (3 items). The basis for answering all questions and also for scoring are the Consensus Reports (6 articles) published by the ECFS, see page 7 of this newsletter.

Furthermore, Daniela d'Alquen has prepared a list with additional literature concerning guidelines/consensus statements (search words PubMed) in Cystic Fibrosis. This list and electronic copies of all articles were sent to all participants.

Jitka Brazova presented the quality assurance program, a summary of her presentation is published elsewhere in this newsletter.

Thomas Wagner presented the first draft of the patient questionnaire. During the meeting the participants concluded that the patient questionnaire should not have more than one page, if possible. The questionnaire will be distributed over the website system (no paper mailing, etc.) to those who have asked a question. This is only a segment of the patient population but this is the group we are addressing – with the help of the national patient organisations.

The webdesigner Michael Gotzen showed that the system is technically ready and that all contents received so far can be included in the local websites for each language; he did a round tour through the system in the roles as a „user“, „moderator“, „editor“=expert and „coordinator“. Finally, he presented how the local websites will be launched. Each local website will be a subdomain of [www.ecorn-cf.eu](http://www.ecorn-cf.eu), and all pages are hosted by Frankfurt.

To get ECORN-CF fully successful it is necessary that the collaborative partners can be motivated to join in. New partners should be aware that: They will be included in the system, receive a subdomain on the ECORN-CF website. They have to translate the texts for the website, have to build a team of experts (provide CV, e-mail address) but they do not receive money.

They should come to the Quality Round Tables but have to find their own funds to pay the travel costs.

There will be one subdomain for every language zone, not for every country. For example, the local expert advice in French could consist of Belgian and French experts, similar to the Dutch domain which will consist of Belgian and Dutch experts.





### Forthcoming issue

The next three local expert advices to be launched are the Lithuanian, Romanian and Swedish expert advice. Furthermore, the Dutch and Polish expert advice will follow as soon as possible.

Our next newsletter is planned to be published in February 2008.

### Contacts

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### Forthcoming event

Second Quality Round Table: Prague, April 22-24, 2008