



ECORN-CF: www.ecorn-cf.eu

Editorial, by Jeannette E. Dankert-Roelse

Editorial

1

Questions are never indiscrete, answers sometimes are

Second Quality
 Round Table, Prague

1

The above mentioned saying from Oscar Wilde, should never be applicable for ECORN-CF: the quality checks and the Quality Round Tables which are organized twice yearly should guarantee that all answers are correct, understandable and friendly.

To publish or to
 perish: actions to get
 more publicity for
 ECORN-CF

5

During the second Quality Round Table that was held in Prague at the end of April 2008 a very enjoyable atmosphere was created which enabled in-depth discussions between the participants of the meeting. Many topics debated during the meeting are discussed in this newsletter.

Preliminary program
 meeting November
 2008 in Frankfurt

6

A main concern that was expressed by many is how we can attract more people and make them visit the local websites and ask more questions. A first necessary step seems to make more publicity for the existence of ECORN-CF and the possibilities it offers for lay people as well as for professionals with an interest in CF. Quite a lot of ideas came along and a few of them were worked out and are discussed in this newsletter, but more ideas are still welcome!

As the name of the meetings already suggests, quality and continuously improving it, is a main goal of ECORN-CF. All answers have to be checked and double-checked before they are published. Whether the present expert advice system that worked out very well in Germany is optimal within a European setting is still uncertain. Read in this newsletter more about the ideas that live among the associated partners about this subject.

The scoring system set up within ECORN-CF, although primarily meant for improving the quality of the answers appears to be very helpful in detecting the first problems that arise during answering questions, such as the use of brand names in questions, how to handle misspelling and grammar mistakes in the questions when making question-answer pairs ready for publication. After these problems are solved the second move is to improve the quality of the given answers by a fine-scoring system.

From the frequently asked questions it appears that CF-patients grow up healthier than ever, and they behave like their peers: they travel around the world. Through the contacts and the experience that will be built up, it is conceivable that ECORN-CF may help CF-patients getting not only correct answers on their questions about traveling but also the best possible care for their disease during their journeys in all European member states.

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

This meeting was excellently organized by Jitka Brázová, together with Milan Macek leader-of Work package 6 of ECORN-CF,(Quality Assurance).

Participants of this meeting, all involved in the ECORN-CF network, came from Belgium, Czech Republic, Germany, Netherlands, Lithuania, Romania, Sweden and the United Kingdom. Guy Dargent participated as representative of the European Commission (Public Health Executive Agency, PHEA). In total there were 22 participants of this meeting.



The meeting started with welcomes from Thomas Wagner and Jitka Brázová. Jitka explained the program of the meeting and provided the participants with interesting background information about the CF-center in Prague.

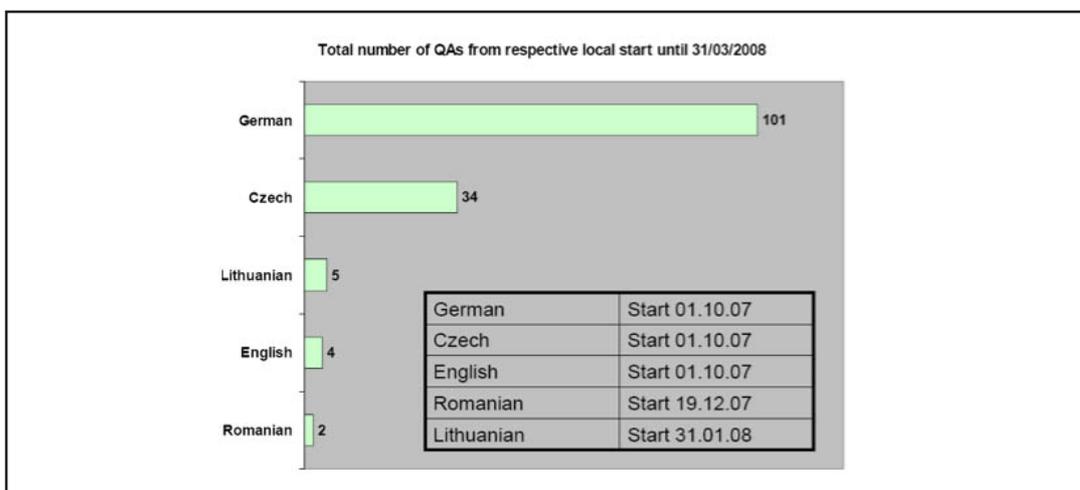
Topics of the meeting

An important item during this meeting had to be the way questions are asked and answered, and how they should be handled in a professional way. Another focus of the meeting was how to achieve answers that meet the required quality. Therefore a number of questions and answers were prepared and presented by editors of local websites, and discussed by all participants.

Some statistics

First, Annette Pfalz explained how the moderators of the local websites can find the current situation of the questions and answers (QAs) on the ECORN website. Editors and other users do not have access to this 'statistical' part of the website. During the meeting Annette presented the data available so far.. Then, all participants discussed the presented figures.

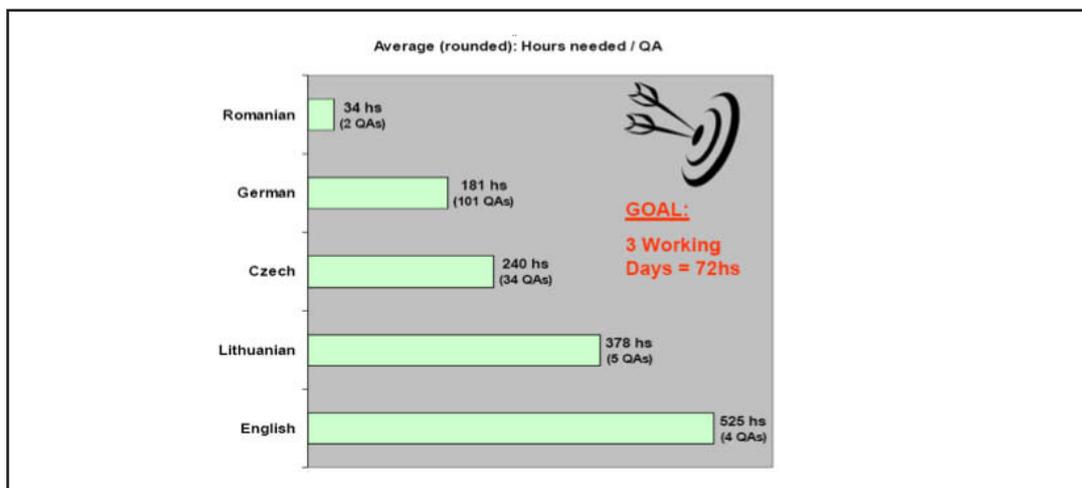
In the graph below the distribution of the number of QAs is shown. There is a remarkable difference between the expert advice in English, German, and Czech, although the websites started at the same date.



The participants from the UK explained that the most probable reason why so few questions have been asked in the English language expert advice is that there is already an offer called "Ask the Expert" by the UK CF patient organization. During the discussion the proposal was made to send QAs from "Ask the Expert" for quality check. After this quality check the QAs can become part of the ECORN-CF archive. Another proposal was to link "Ask the expert" with ECORN-CF. To get more publicity for ECORN-CF it was decided to initiate further actions (see page... of this newsletter).

Differences were also observed between the 5 websites in the average number of hours necessary to answer a question. The initial target time aimed for at that time was 72 hours or 3 working days.

As can be seen from the graph below this target time was not realistic. However, the presented figures represent an average of the time spent to answer a question; a few questions that were difficult to answer and therefore took a long time, can have had a strong influence on the calculated average. After having looked at the data again, especially with regards to the distribution of the time spent for each question, the coordinator decided to skip the target time of three working days. From July 2008 on, the questioners are informed as follows: "We try to answer your question as quickly as possible, but quality has the priority over speed. So, please, understand that it may take a couple of extra days if reassurance with other experts is necessary". When several experts cannot agree about the answer, an answer should be given explaining the different opinions with a final deadline of one month after the question was posed. It is important that questioners do realize that the reference network is not meant for emergencies.



More about asking and answering questions

Lay persons

A problem frequently encountered is that users ask more than one question at the same time. In the answer the questions have to be split up and answered separately. For the users of the website it is important that a user instruction "how to ask a question" is available on the website. It was agreed that this instruction has to be translated in all languages and will be placed on the local websites. Moreover, the number of characters allowed in a question will be reduced to prevent too extensive questions. A further point in the debate was how to handle mistakes in spelling and grammar in the question. It seems better not to correct these because the goal of the website is to provide a meta communication forum.

Professionals

The number of questions from professionals is at present also much lower than expected. It seems important to get more publicity about the ECORN-CF expert advice project among professionals as well. Therefore the actions to get more publicity will be aimed not only at patients but at professionals as well.

The scoring system

During the meeting much attention was paid to the quality of the answers that are given. The first goal is that all answers should have the required quality and the second that the quality of the answers improves with time. Therefore two scoring systems are used.

1. The first system is used to do a quality check on the answers as edited by the expert. The editor or coordinator assesses the content of all answers before these are published in the English ECORN-CF Archive. During the assessment answers can be scored as good, acceptable or with flaws. An answer is scored "good" when it addresses all aspects of the question AND is in accordance with the guidelines or the available evidence. It is scored "with flaws" when it is incomplete OR not in line with the guidelines on minor points. It is scored "unacceptable" when it doesn't answer the topic of the question or is in contrast with the guidelines. Answers are assessed on content as well as on style. The content of the answers should be correct and according to the guidelines, it should be complete and cover all aspects of a question, and it should be open but at the same time avoid too strong statements which may be in conflict with the opinions of the own CF-centre of the patient. The style of the answers is equally important. The answer should be written in understandable language for the layperson and avoid medical-technical terms; the answer should address the questioner in a friendly manner; and the extent of the answer should be suitable for the question and with sufficient details.
2. The second system is used to get more insight whether the quality of the answers improves during the course of the project. A random sample of questions will be extracted for scoring from the beginning, the middle and at the end of the project. Three to five persons will score the QAs for the given answers.

A number of encountered problems were discussed.

- **Should each QA be published?**

Questions which are only of local relevance, for instance questions about local social security systems, will not be published in the English archive, only on the local website.

- **Should each question be counted for statistics?**

Questions not related to CF should not be answered and therefore not be counted.

- **How to handle answers naming specific brands or hospitals?**

In the case brand names of medicines are used in the question the editor will replace these in the answer by the generic name of the medication. Only generic names are used in the English Archive.

- **How should corrections or additional information for a previously answered question be published?**

This topic led to a discussion about the system of local experts who first answer the question and publish this on the local website (after quality check of the local moderator), while the European level quality check and possible additional corrections take place only after translation of the QAs in the English language. It was put forward that for a European expert advice, more questions from laypersons as well as from professionals might be attracted if they were answered by an international team and not only by the local team. Other possible advantages would be that the process of training the local experts and learning from each other, which are important aims of ECORN-CF may be quickened and that it reduces the risk of not fully correct answers. In the discussion that followed the participants agreed that the added value of the European quality check should be made visible to every user. This process reduces the risk of incomplete or incorrect answers, since after feedback answers have to be corrected on the local website. It has to be ensured that the questioner in every case sees the corrected answer. Also the discussants agreed not to change the present set-up of ECORN-CF where the local experts provide the answers; these experts get trained by answering the questions according to the guidelines and European consensus.

- **It was stressed that for the sake of fine scoring and complete communication it is important to translate the whole question and answer.**

Questions and answers

In the afternoon eight selected questions and answers were discussed. During this discussion most of the answers appeared to have been satisfactorily answered. For 1 QA the participants of the meeting decided to add new information, and for another QA another conclusion was reached than the local expert that answered the question. For the last QA a new answer will be written. For some frequently asked questions such as about "Traveling with CF" it would be helpful to spend a part of the next meeting to achieve consensus and develop guidelines

To publish or to perish: actions to get more publicity for ECORN-CF

A main concern about ECORN-CF during the meeting in Prague is the slowness of the process of getting laypersons (CF-patients themselves, their parents or relatives and friends) as well as professionals connected with CF interested in the use of ECORN-CF. The website can offer already an expert advice for every-one who needs advice, but the important goal of improving these services can only be achieved when the website is visited more often. Although this is realized already for the German and Czech websites, in other language zones the process is much slower. It seems, therefore, that there is a need for more publicity of the project.



The first event to get more publicity was the ECFS-meeting that was organized in Prague in June 2008. During the meeting a special ECORN-CF stand with a laptop was present in the exhibition hall.

Special informative flyers were given together with the conference bag to each participant of the conference. More flyers were available on the ECORN-CF desk. Members of the organizing committee were present at the desk during coffee and lunch breaks and helpful to explain the use of the ECORN-CF expert advice service. Also the existence of the ECORN-CF project was extensively mentioned during one of the plenary sessions.

Other actions to make ECORN-CF more widely known could be organized with the help of the local CF-patient organizations. A whole list of possible actions to attract more questions from lay

and professional users was put together (further additions are welcome):

- Local CF-patient-organisations should definitely put a link to the ECORN-CF website on their home-pages,
- They should be asked to report (regularly) about the services and activities of ECORN-CF ('The interesting question of the month', etc.)
- All professional societies (pediatrics, respiratory diseases, physiotherapy, etc.) should be asked to put a link to the ECORN-CF website on their home-pages
- They should be asked to report (regularly) about the services and activities of ECORN-CF ('The interesting question of the month', etc.)
- Health insurance and public health authorities should be asked to put a link to the ECORN-CF website on their home-pages
- Present the flyer on all occasions (English version)
- Translate the flyer to YOUR language, present this on all possible occasions
- Send the flyer to all CF-centres in your language zone
- Offer to have the flyer printed with local additions (show your CF-team)
- For each of these actions: write a short press release, send it to the media including all daily and yellow press, they love this and they are read...

The text of the flyer will be sent to all participating partner to have it translated and make it available in all language zones. The local editors can then circulate the flyers in the local languages among the national CF-centres or put the information as a leaflet in the newsletter of the local CF-organisations.

A short article about ECORN-CF will be put on the homepage of the EU initiative "Orphan diseases" as well. This can be translated and used as one general type press release for your local expert advice. Add some personal story of a young lady patient who really felt this was very helpful... the media will like it...

Another proposal was to give the ECORN-CF project more publicity during the ERS-meeting which will be held in Berlin, 4-8 October 2008

Preliminary program meeting November 2008 in Frankfurt

The next meeting will be held again in Frankfurt, Germany, on November 4, 2008. With improving prognosis and living in a global village CF-patients travel around the world more and more; the ECORN-website could be the ideal forum to get information about safe traveling for CF-patients and their travel-partners. Therefore a consensus meeting will be organized about the topic "Traveling with CF", in the morning of November 5th.

Preliminary program of the 3rd Quality Round, Frankfurt, 3-5 November, 2008

During this meeting we hope to meet not only the associated partners but also representatives from our collaborating partners from other language zones! Ask for further information Annette Pfalz, administrative coordinator of the project (e-mail: pfalz@em.uni-frankfurt.de)
Contacts:

program meeting November 2008, Frankfurt

Monday - Nov 3, 2008

For those arriving the day before the meeting

From	Until	Topic	Responsible
19:00		Meeting at lobby of IBIS Hotel, dinner at a close-by restaurant	Annette Pfalz

Tuesday - Nov 4, 2008

3rd Quality Round Table of ECORN-CF

From	Until	Topic	Responsible
10:00	10:15	Greeting, program of meeting	Thomas Wagner
10:15	11:15	WP4: Results of finescoring, discussion	Helge Hebestreit, Daniela d'Alquen
11:15	12:15	Overview about financial matters, some statistics Time for questions, discussion	Annette Pfalz Thomas Wagner
12:15	12:45	Discussion of the most interesting questions in ECORN - No. 1	tbc
12:45	13:45	Lunch Break	
13:45	14:15	Discussion of the most interesting questions in ECORN - No. 2	tbc
14:15	14:45	Discussion of the most interesting questions in ECORN - No. 3	tbc
14:45	15:15	Discussion of the most interesting questions in ECORN - No. 4	tbc
15:15	15:45	Coffee Break	
15:45	16:30	Presentation: How to use the system of ECORN-CF (with internet access), time for questions	Annette Pfalz
16:30	17:15	Implementation of a ECORN-CF consensus program / What can ECORN-CF learn from ECFS-consensus program - introduction (approx. 10 - 20 minutes)	Gerd Döring
		Discussion	All
17:15	17:30	Short Break	

17:30	19:00	Consensus Meeting: Travelling with CF: Prevention of <i>P. aeruginosa</i> infection - brief introduction (10 - 15 minutes)	Thomas Wagner, Tim Hirche, all
		Discussion; further topics (e.g. travel destinations)	All
19:30	21:00	Dinner	

Wednesday - Nov 5, 2008

Consensus Meeting - Travelling with CF"

From	Until	Topic	Responsible
09:00	10:30	Consensus meeting	Thomas Wagner, Tim Hirche, all
10:30	10:45	Short Coffee Break	
10:45	12:00	Consensus meeting	Thomas Wagner, Tim Hirche, all
12:00		End of meeting, snacks to go	

Contacts

ECORN-CF project leader:
Prof.dr. Thomas O.F. Wagner

Annette Pfalz (coordination and adminstartion)
Pneumologie/Allergologie (Prof. T.O.F. Wagner)
Medizinische Klinik 1 / Haus 15 B
Klinikum der Johann Wolfgang Goethe-Universität
Theodor-Stern-Kai 7
D - 60590 Frankfurt am Main

Tel +49-(0)69-6301-3824
Fax +49-(0)69-6301-6335
E-mail pfalz@em.uni-frankfurt.de

Public relations work package leader:
Dr. Jeannette E. Dankert-Roelse
Sandra Reijntjens, secretary
Kindergeneeskunde
Atrium medisch centrum Heerlen
Postbus 4446
6401 CX Heerlen

Tel +31 45 5766931
Fax +31 45 5767154
E-mail SRS07@atriummc.nl