



ECORN-CF: www.ecorn-cf.eu

Editorial, by Jeannette E. Dankert-Roelse

Celebrating Events in 2009

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To me the number of events that are memorized this year seems to increase every day; 2009 is not only the Darwin-year, but we also think back about the first steps of manhood that were set on the moon in July 1969, and to the first escapes of people from behind the Iron Curtain at the border of Hungary and Austria in August 1989. This last event was the start of the crumbling down of the Iron Curtain, leading to the opening of the Berlin Wall in November 1989 and the first step to the expansion of the EU in 2007.

Another important event which was memorized during the ECFS in Brest was the discovery of the CFTR gene and the most common mutation in that gene causing CF, 20 years ago. This was published in the Science edition of September 8, 1989. This event was celebrated with the ECFS Award jointly presented to Prof. Lap Chee Tsui, Prof. Batsheva Kerem, Prof. Francis Collins and Prof. John Riordan. Since 1989 this discovery has led to new insights in the pathophysiology of CF, as well as to improved diagnostics and neonatal screening. The new knowledge about the basic defect also led to many efforts to develop new treatments currently in the pipeline but not yet available for patients with CF. But every worker in the field of CF hopes that this may change soon.

Another historic milestone that should be remembered in 2009 is the fact that 40 years ago the first exchange via the Internet occurred, at first only symbols, but soon the two computers linked by an Internet connection also exchanged comprehensible words. To what a development this finding has led! And it is the basis of ECORN.

In this newsletter we report about a new member of ECORN, Greece, about the increasing number of questions on practically every local website and about activities of ECORN during the ECFS. Finally you will find the program of the next Round Table meeting in Prague. We hope to meet there all participants and everyone who has an interest to start a website within ECORN!

News

On March 25, 2009 the website of a new participant in ECORN-CF.EU was launched. We are happy to announce that the Greek website started with passion. Congratulations to this expert-team that took up this challenge! This means that a new language-zone is now joining the efforts of ECORN-CF.EU to create a forum for many people throughout Europe to ask questions and find answers about all aspects of CF that they encounter in daily life. Especially for patients speaking and reading Greek as their mother language it might be difficult to find answers to their questions on the Internet. We expect therefore that in this language zone the ECORN website will be an important source of information for the Greek lay people with an interest in CF and for the Greek CF-teams.

The Greek team does not get any funding but their experts are enthusiastic about participating in the project. They do all the translation work and are willing to answer all questions that come to them.

Αρχική Σελίδα | Αρχείο ECORN-CF | Επικοινωνία | Ελληνικά (Επιλογή Γλώσσας)

ecorn-cf.eu
Expert Advice on Cystic Fibrosis

Συμβουλές ειδικών

Συμβουλές ειδικών Central Archive Ομάδα ECORN-CF Τοπικοί Συνεργάτες Κινητική Έκδοση

Θέματα

Δf_508 κυστική ίνωση παγκρέατος
ΘΑ ΠΡΕΠΕΙ ΚΑΤΑ ΤΗΝ ΕΞΕΤΑΣΗ ΝΑ ΕΙΝΑΙ ΠΑΡΟΝΤΕΣ ΚΑΙ ΟΙ ΔΥΟ ΚΑΙ ΑΝΤΡΑΣ ΚΑΙ ΓΥΝΑΙΚΑ Ή ΜΠΟΡΕΙ Η ΕΞΕΤΑΣΗ ΝΑ ΓΙΝΕΙ ΞΕΧΩΡΙΣΤΑ.
06.04.2009

Έλεγχος ακοής
Χθες ο επτάχρονος γιος μου πέρασε από τον ετήσιο έλεγχο στο κέντρο ΚΙ. Η ΤΚΕ, ο υπήρχος, κτλ, ήταν όλα φυσιολογικά. Πρέπει να περιμένουμε ακόμη τις απαντήσεις για ...
05.01.2009

Οστεοπόρωση
Ποιο είναι το πιο πρόσφατο θεραπευτικό πρωτόκολλο για νεαρούς ενήλικες με ΚΙ και οστεοπόρωση; Θα ήθελα πληροφορίες σχετικά με τα φάρμακα και τη διατροφή.
05.01.2009

Θέματα

Κάντε μια Ερώτηση
Προφίλ χρήστη
Αναζήτηση
QA list for moderators
QA list for local editor
User Guides
Edit Keywords
Statistics
Reference documents

A short introduction to the Greek expert team



- **Dr. Eleftherios – Stavros Doudounakis**
Director of the Cystic Fibrosis Department, Aghia Sophia Children's Hospital, Department of Cystic Fibrosis, Athens, Greece.



- **Dr. Anna Katelari-Ioannidou**
Aghia Sophia Children's Hospital, Department of Cystic Fibrosis, Athens, Greece.



- **Konstantinos D. Katsoulakis**
Physiotherapist, Physiotherapy Dept. Children's Hospital 'Aghia Sofia', Athens, Greece.

More information about the team members can be found on the ECORN-CF.EU site.

Questions and answers

Since the ECORN project started about 2 years ago with a kick-off meeting in Frankfurt, one starts wondering what the project has achieved in the meantime. One way to measure if ECORN achieves its goals is to take a look at the number of questions and answers published in the Central Archive. All QA's published in this Central Archive are quality checked.

This is what you would find if you clicked on Central Archive on April 30, 2009

Displaying results 1 to 10 out of **396**

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But if you clicked on it on August 17, 2009 you would have got this screen:

Displaying results 1 to 10 out of **509**

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This means that the number of questions and answers is rapidly increasing. Within 3,5 months the number of published QA's increased by more than 25%. When clicking on the questions and finding the answers displayed on the same screen one soon finds that questions come from many countries, e.g. from Italy (although not yet participating in ECORN-CF!), Romania, Germany, Czech Republic, UK. And I know from my own experience as member of the Dutch-Flemish expert team that the number of questions from Belgium and the Netherlands is steadily increasing as well. One should also realise that not all questions are published in the Central Archive. Questions of only local interest (for instance about law or social security matters) are not published in the Archive.

Table 1 shows an overview of the total numbers of questions categorized by country and by time period, the total number of questions and answers published on ECORN-CF and the total number of questions and answers published on the Central Archive. Generally speaking, for starting websites the numbers of QA's are steadily rising, while for websites that are already longer on line the numbers seem to stabilize. As expected the total number of QA's published on the Central Archive is lower than the total number of QA's published on the local websites.

Table 1. Numbers of questions published on the local websites and in the English Archive, divided in 3 time periods (of 12, 6 and 6 months)

Country	Online since	No of published questions			Total No
		May 1, 2007 - Apr 30, 2008	May 1, 2008 - Oct 31, 2008	Nov 1, 2008 - Apr 30, 2009	
Germany	October 1, 2007	106	79	90	245
Czech Republic	October 1, 2007	36	34	21	91
UK	October 1, 2007	4	12	19	35
Romania	December 19, 2007	3	3	13	19
Lithuania	January 31, 2008	4	7	10	21
Belgium/NL	March 5, 2008	0	13	44	57
Poland	April 10, 2008	0	1	13	14
Sweden	October 13, 2008	0	0	0	0
Greece	March 25, 2009	0	0	1	1
TOTAL		153	149	211	513
Archive TOTAL	October 1, 2007	89	60	245	394

Table 2. Overview of the evaluation of the QA's

The state of QA's on April 30, 2009	No
Q/As published in the Archive	394
Q/As with "guideline available"	67
Q/As with "Answer according to guideline" (if guideline exists)	59
Q/As with "Guidelines still needs to be worked out"	18
Q/As scored "good"	319
Q/As scored "with flaws"	39
Q/As scored "unacceptable"	3

When answering questions, it is not only the quantity that matters but at least as important is the quality of the given answers.

The quality of the answers is assessed continuously, in Table 2 an overview is given of the present situation of the assessments. When an answer is considered being "with flaws" or "unacceptable" the quality team contacts the original local language team that answered the question suggesting an amended answer in English. Once, the new, amended answer is agreed upon the original local team is asked to re-translate the amended English answer into their language and to put this answer on the local website as well. If the questioner asked the question not anonymously but in a registered mode, he/she will be informed by e-mail that the answer was changed.

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

All associated partners discuss the results of these evaluations during the Quality Round Tables. The next Quality Round Table will be held in Prague, 6-7 October 2009.

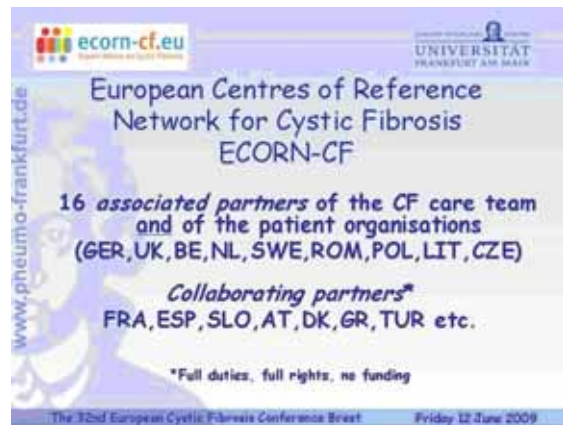
The most requested subjects can be seen in the keyword list. The keywords are of a general nature.

All areas of CF care are covered, as can be seen from this keyword list. The most prominent ones are: general aspects, genetics, Pseudomonas, and travelling.

ECORN Activities during the ECFS

A few weeks before the ECFS, Judy Bradley carried out a survey among the 16 associated partners in ECORN to list the ways how CF centres manage adults with mild CF and she gave a presentation about her findings during the meeting.

During the session "Identification of best practices", Christoph Baltin explained the goals of ECORN, the way the quality of the given answers is assured, and presented some results since the start of ECORN in May 2007.



Programme 4th Quality Round Table and Consensus Meeting, Prague, 5–7 October 2009

	From	Until	Topic	Responsible
Monday - Oct 5, 2009	19:00		Dinner at "Hotel Meritum" for those arriving the day before the meeting	Ivana Funková

	From	Until	Topic	Responsible
Tuesday - Oct 6, 2009				
	9:00	9:15	Greeting, program of meeting	Jitka Brázová
30'	9:15	9:45	Mixed issues	Annette Pfalz
90'	9:45	11:15	WP4: Results of finescoring, discussion	Daniela d'Alquen
60'	11:15	12:15	The future of ECORN-CF after April 30, 2010	Thomas O.F. Wagner
30'	12:15	12:45	Discussion of the most interesting questions in ECORN (1) - ABPA	Judy Bradley
60'	12:45	13:45	Lunch at "Hotel Meritum"	Ivana Funková
30'	13:45	14:15	Discussion of the most interesting questions in ECORN (2) - Prophylactic/permanent antibiotic treatment	Jeannette Dankert-Roelse
30'	14:15	14:45	Discussion of the most interesting questions in ECORN (3) - Swine flu	Anne Malfroot
30'	14:45	15:15	Discussion of the most interesting questions in ECORN (4) - ... early therapy of PSA	Jitka Brázová
30'	15:15	15:45	Discussion of the most interesting questions in ECORN (5) - "... therapy of chronic PSA"	Ernst Rietschel
15'	15:45	16:00	Short Coffee Break	Ivana Funková
45'	16:15	17:00	Introduction: Consensus paper "Travelling and CF"	Tim Hirche
45'	17:00	17:45	Consensus paper "Travelling and CF"	Birgit Dembski
45'	17:45	18:30	Consensus paper "Travelling and CF"	Karleen de Rijcke
	18:30	*****	End of this day's meeting	***** *
	19:00	21:30	Dinner at restaurant "U Prince"	Ivana Funková
Wednesday - Oct 7, 2009				
Consensus Meeting - Travelling with CF	9:00	10:30	Consensus paper "Travelling and CF"	Thomas Wagner, Tim Hirche, all
	10:30	10:45	Short Coffee Break	Ivana Funková
	10:45	12:00	Consensus paper "Travelling and CF"	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 administration)
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 info@ecorn-cf.eu

Public relations work package leader:
Dr. Jeannette E. Dankert-Roelse
Sandra Reijntjens, secretary
Kindergeneeskunde
Atrium Medisch Centrum
Postbus 4446
6401 CX Heerlen
Tel +31 45 5766931
Fax +31 45 5767154
E-mail SRS07@atriummc.nl