Cystic Fibrosis European Network

NEWSLETTER

JULY 2001 – N° 5

CONTENTS

NEWSLETTER CONTRIBUTIONS

The closing date for the next issue of the CF Thematic Network newsletter is September 30, 2001.
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EDITORIAL

Dear friends and colleagues,

The end of the academic year is for most of us, hopefully, the beginning of a period of some rest but also a unique occasion to do things we have not been able to tackle during the year. This pseudo-inactive period is also a good time to reflect on what was done and what was not or partially realised.

The Thematic network cannot be blamed for inactivity. The 'Methods and Procedures' meeting in Lisbon, organised with the support of the Network, was again very successful and is enjoying an ever-increasing quality reputation in CF circles. The Resources website does already contain quite some impressive information about tools and procedures. The Network was officially present at the ICHG meeting and again at the ECFS meeting, both in Vienna. We organised a symposium and a workshop, which attracted quite a crowd. Also at the ECFS meeting the thematic Network offered representatives of the European patient organisations the opportunity to meet in order to start the creation of a European platform for CF patient organisations. This platform will in time become the privileged partner of our European science and diagnostic activities. In the mean time the diagnostic laboratories have received the results of the last QA scheme and the next one is in full preparation. We still have not reached the 100% correct testing.

More and more industrial partners are expressing their interest in the activities of the network and will join us in a meeting in November, to discuss their needs and offers of collaboration.

You will receive again in this issue of the newsletter quite some information on the activities of the network. Are we doing well? We think so. But doing even more is always possible. Let us know if you have suggestions or constructive criticism.

In the mean time have a restful and refreshing vacation and come back with lots of energy to tackle the next activities of the network.

Jean-Jacques Cassiman
Coordinator of the CF-network
Leuven, July 2001.

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CF ASSOCIATIONS MEETING
Leuven, March 9, 2001

Two representatives of 9 European CF associations (Belgium, Denmark, France, Germany, Ireland, Spain, Sweden, The Netherlands, United Kingdom), ICF(M)A and WHO were invited for a short meeting of the European CF network**,** organised in Leuven, Belgium March 9, 2001**.** The main aim of the thematic network is to create a unique platform for fundamental CF research, for diagnostic laboratories, for CF associations of families, patients and clinicians, ethical, legal and intellectual property rights (IPR) experts, and representatives of the industry, and to stimulate the interaction between all participants.

After an introduction given by the coordinator of the network Jean-Jacques Cassiman, Els Dequeker explained all the different information channels (like the newsletter, web page, meetings,….) used by the network. The different groups involved in the network (scientist, geneticists, industry members, ethical and legal experts) were introduced by Jean-Jacques Cassiman with a short summary of their activities.

The group of Herman Nys (Leuven, Belgium) is preparing together with other members of the steering committee of the thematic network an informed consent for DNA sampling and guidelines of genetic testing. The draft version of the informed consent was presented. After adapting some remarks, it was sent to all the CF associations for further comments.

After explaining what the CF network consists of, the question raised by the network was formulated as "gathering the European CF associations". An open discussion was held, and it was decided to organise, with the help of the EU CF network, a meeting on this issue in Vienna. Herman Weggen will organise this meeting.

Further it was planned that a second meeting should be organised for the CF associations in 2002.

Els Dequeker, Leuven, Belgium

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CFTR WORKING GROUP - 2001 MEETING
Estoril, March 30 – April 1, 2001

The '*Second Consensus Meeting Towards Validation of CFTR Gene Expression and Functional Assays*' took place between 30th March (Friday) and 1st April (Sunday) in Estoril, near Lisboa with 74 participants from several EU countries (Belgium, Denmark, France, Germany, Greece, Ireland, Italy, Netherlands, Portugal, Spain, Sweden and UK) as well as from outside the EU (Canada, Switzerland and USA). The programme consisted of 6 main sessions, chaired by the respective Rapporteurs (corresponding to the 6 thematic areas of the CFTR-Working Group), namely: **A. Transcript Analysis** (A Harris) with 9 presentations; **B. Cell Biology and Histology** (E Puchelle) with 8 presentations; **C. Protein Biochemistry and Biophysics** (A Edelman) with 8 presentations; **D. Cellular Physiology** (D Sheppard) with 9 presentations; **E. Functional Assessment** (B Tümmler) with 6 presentations; and **F. Models in CF Research** (B Scholte) with 8 presentations. Additionally, two more plenary sessions on novel methodologies were included in the programme, namely: **GI – Global Analysis of DNA and RNA** (3 presentations); and **GII – Proteomics** (2 presentations).

Formal discussions on the 8 thematic areas of the plenary sessions (plus another one on the '*Virtual Repository*') took place at '*Breakfast and Morning*' (Saturday) and '*Wine and Cheese*' Roundtables (Saturday, late afternoon). Informal discussions also took place during the whole meeting in general and at the '*Disco/Swimming pool border discussions*', in particular. A dinner party took place on Saturday night at Museu Condes de Castro Guimarães (Cascais) and the *'Tuna'* of students from the two Medical Schools in Lisboa were in charge of entertaining the guests with their lively songs.

On Sunday morning the '*Conclusions'* from the 6 main thematic areas, drawn not only from the plenary sessions but also from Roundtable discussions, were presented by the respective Rapporteurs (and will be published in the June issue of this Newsletter). A questionnaire about the meeting was distributed among participants in order to obtain their anonymous opinion about it. A first analysis of these filled questionnaires already took place and the general opinion about the meeting is rather positive: very good - 63%; good - 37%.

The *Third Consensus Meeting Towards Validation of CFTR Gene Expression and Functional Assays'* will take place between 12-14 April 2002 near Lisboa, in a place to be announced. We hope you all can attend it and in the meanwhile, we count on your contributions to the Working Group in order to improve it and to help it achieving its goals.

Margarida D Amaral, Lisboa, Portugal

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REPORT ON THE
WORKSHOP ON RISK CALCULATION
Vienna, May 16, 2001

During the 10th international congress of Human Genetics in Vienna, May 16 - 19, 2001 a workshop on risk calculation was organised by the working group of diagnostic genetic laboratories of the European CF

network. Since 1996, annual QA schemes for cystic fibrosis have been set-up for the genetic molecular diagnostic laboratories in order to evaluate the quality of genetic testing for cystic fibrosis. In these QA schemes, it was observed that many diagnostic labs have problems calculating the correct risks. Mistakes in the interpretation of the data were due in particular to calculating the risk of having a CF child.

Given this observation it was decided to organise this workshop. Prof. Jurg Ott from the Rockefeller University of New York gave a presentation on "Risk calculation for mendelian disorders" and Prof. Cyril Chapmann from Oxford, UK on "Computer assistance with risk calculation". The slides of the presentations can be downloaded from the web site of the network (www.cfnetwork.be). More than 400 participants attended the workshop. Suggestion for topics - subjects for the next workshop are welcome.

Els Dequeker, Leuven, Belgium

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CF ASSOCIATIONS MEETING DURING THE 24TH EUROPEAN CF-CONFERENCE
Vienna, June 6, 2001

Present

Herman Weggen, president ICF(M)A, Gina Steenkamer, secretary ICF(M)A and representatives of the Belgian, Czech, French, German, Hungarian, Italian, Norwegian, Slovakian, Swedish and U.K. national CF associations

Introduction

After the ICF(M)A meeting in Vienna, representatives of several European CF Associations gathered to discuss the foundation of a European CF platform.

Herman Weggen opened the meeting by explaining the history and the reason behind this meeting.

In March 2001, several European associations were invited by Prof. Cassiman to a meeting on the CF European Network in Leuven (Belgium). The need for gathering the European CF associations was raised there and Herman Weggen was asked to organise a first meeting during the conference in Vienna. Herman Weggen mentioned that, after organising this first meeting, he withdraws from any further commitment with a European group, since he prefers to concentrate on his responsibility with ICFMA.

Structure

Everyone agreed about the need for a European CF platform.

There was some discussion about creating a formal or informal structure. Some participants felt it was too early to decide on the structure, since we have to decide first what we want, where we want to go and how we want to work. But it's important to form a formal structure to be recognised on a European level and to get access to European funding. Also there are urgent requests from several organisations (e.g. CF Network, Registry, ECFS,…) for 1 official European patient body, to represent the European point of view of CF patients.

It was therefore decided to form a regional group within ICF(M)A (and later in "CF World").

Working group

A working group consisting of representatives from 5 national associations (Belgium, Czech Republic, Germany, Sweden, and U.K.) was elected to work on a more concrete proposal. They were invited by the Swedish association for a first meeting in Stockholm, 13-14 October 2001.

Every European association is asked to forward any suggestions, ideas, remarks, … for the formation of a European CF platform to Inge-Britt Lundin before the end of September 2001:

Mrs. Inge-Britt Lundin
Upplandsgatan 49 V
S-11328 STOCKHOLM
Tel. home: ++46 8 320724/ office: 8 737 3309
Fax office: 8 737 4188
E-Mail Office: inge-britt.lundin@lk.sll.se
E-Mail Home: inge-britt.lundin@stadshuset.stockholm.se

Karleen De Rijcke, Brussels, Belgium

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REPORT ON THE SECOND ANNUAL SATELLITE SYMPOSIUM OF THE CF NETWORK
Vienna, June 8, 2001

It was proposed in the EU project that annual symposia should be organised aiming to inform as much as possible participants on the progress of the project and related subjects. At the annual meeting of the European CF network in 2001, a separate session was organised as a part of the official program of the 24th European CF-conference in Vienna.

Seven lectures on different topics were held:

AN EUROPEAN WORKING GROUP ON CFTR EXPRESSION AND FUNCTION

Margarida D. Amaral
Faculdade de Ciências da Universidade de Lisboa and Instituto Nacional de Saúde Dr. Ricardo Jorge

Despite rapid advances in molecular determinants of the disease since cloning of the cystic fibrosis (CF) gene, for most *CFTR* gene alterations described, the respective pathological consequence for CF remain poorly understood. It is thus

important to establish and/or develop reliable methods and assays that can be adopted by most CF laboratories in order to evaluate either *in situ*, *ex vivo* or *in vitro* parameters of CFTR expression and function that can be adopted with confidence for the diagnosis of CF and, possibly also for disease prognosis.
Although an impressive amount of research is carried out in this area, controverse results often arise in the CF field. This fact, however, may be partially due to the use of different *experimental procedures*, or because studies were performed in different *tissues/organs*. Additionally, the use of a *plethora of models*, introduces further variability. There is thus the need for a common strategy to study CFTR gene expression and function, through the establishment of consensus methodologies and sharing reference biological materials. This is the gap that this Working Group intends to fill, as part of the EU-sponsored *Thematic Network around Cystic Fibrosis and Related Diseases*.
Thus, the main objectives of this European Working Group on *CFTR Expression and Function* (CFTR-EWG) which started in 2000 include: 1) setting-up a system of reagent production and access (i.e., a 'Virtual Repository of Methods and Resources'); and 2) dissemination of consensus experimental protocols. To fill these objectives several tasks are undertaken.
The CFTR-EWG includes **six thematic areas** and for each a Rapporteur (i.e., a Scientific Coordinator) has been assigned. These areas are: a) Transcripts analysis; b) Cell Biology and Histology; c) Protein Biochemistry/ Biophysics; d) Cell Physiology; e) *In vivo* and *ex vivo* functional assessment; and f) Models.
The CFTR-EWG counts now with a total of 57 members. **Membership** is totally free and open to any scientist in the CF field. Members receive the **Newsletters** on CFTR Expression published 4 times per year. Membership can be applied for through the web page. **Meetings** with members are organised every year to discuss of all six thematic topics, which are open to all scientists in the CF field who are interested in discussing and reporting CFTR expression with a focus on methodological approaches. The CFTR-EWG also promotes the **exchange of scientists** between labs for the acquisition or comparison of methodologies used in CFTR expression studies, by covering travel and accommodation costs. Most information on the CFTR-EWG is available on-line:
http://www.med.kuleuven.ac.be/cme/cf/CFTRExpression.htm.
Finally, we hope that the work of the CFTR-EWG is useful for basic research in the CF field, as a common platform between researchers and resources aimed at generating consistent insights into the CF disease and to create innovative diagnosis/therapeutic approaches to the ultimate benefit of CF patients and their families.

INFORMED CONSENT AND PATENT LAW

Pierre Saelen, Geertrui Van Overwalle
Centre for Intellectual Property Rights, Faculty of Law, Catholic University Leuven, Leuven, Belgium

Context: Recital 26 of the EU Biotechnology Directive of 1998 deals with informed consent and patent law. Various national legislators have made a start with the implementation of the Directive in their national legislation.
Aims: To analyse the ethical, social and legal basis for the introduction of an informed consent requirement in patent law. To translate the resulting conclusions into policy suggestions.
Methods: Literature research on the ethical dimension and the social dynamic of informed consent. Analysing whether the informed consent principle is justified in a patent law context.
Results: Two different *ethical* concepts on human autonomy (formal versus substantive autonomy) have led to two opposing concepts of informed consent (formal versus substantive concept). Informed consent is characterised by a *social* dynamic, namely to preserve trust. First, both types of informed consent help to counterbalance medicine's objectifying tendencies, in order to preserve the patient's trust in our scientific medicine. Second, formal and substantive informed consent help to lower the potential risk for lawsuits, in order to preserve the trust of physicians and researchers in their patients.
Patent law can not sanction the lack of informed consent for a patent based on human body material, unless this lack of informed consent is considered as being against "public order and morality". In that case the sanction would be the nullity of the patent. However, this sanction mechanism is only applicable when the exploitation of the invention itself would be totally prohibited. This is hard to imagine.
Conclusions: Existence of a social dynamic requiring informed consent for further use of human material and for the patenting of any resulting invention based on it. Patent law is not an appropriate framework to accommodate an informed consent principle. Therefore alternative legal routes will have to be examined.

CFTR RELATED DISEASES

C. Bombieri and P.F. Pignatti
Biology and Genetics; Dpt. Mother and Child, Biology-Genetics, University of Verona; Italy

CFTR related diseases include isolated respiratory, reproductive, and digestive system diseases, which are also manifestations of CF. Mild signs of multisystem involvement may also be observed. These clinical overlaps pose etiopathogenetic and diagnostic questions. Mutations in the CFTR gene have been found, and this has raised the question of genotype-phenotype correlations, and CFTR mutation type. Genotypes with severe/severe CFTR gene mutations are not generally found in any of these diseases.
1) Some diseases have been confirmed to be associated to CFTR gene mutations. In congenital absence of the vas deferens most individuals carry CFTR mutations (about 80%), most of them (about 60%) have two CFTR mutations. In idiopathic disseminated bronchiectasis, an important fraction carries CFTR gene mutations (about 37%), about half of them 2 mutations.
2) For other diseases or phenotypes, more limited data are presently available. An increase in the frequency of CFTR gene mutations has been found in patients affected by sarcoidosis (EJHG 2000, 8:717), in idiopathic pancreatitis, and in neonates with increased immunoreactive trypsinogen (AJHG 2000, 66:2013).
3) Conflicting reports have appeared for other diseases. We did not find evidence for a CFTR gene involvement in 211 allergic asthma families linkage and transmission disequilibrium analyses.
Also, non-pathogenic CFTR mutations are common in the population, and have been defined as not causing CF purely on the basis of their frequency by screening the whole gene (Hum. Genet. 2000; 106:172). More extended typing of rarer mutations in a larger sample will characterise some still undefined mutations (stage II analysis).
Further analysis of CFTR gene mutation type and expression, of other genes possibly involved, or of still unidentified factors will help in the characterisation of CFTR related diseases.

MOLECULAR PHARMACOLOGY OF CFTR

F.Becq
Laboratoire de physiologie, UMR6558, Université de Poitiers, France.

Searching for active compounds to restore transport function in CF is now recognised as a priority for creating drugs for CF patients. We have investigated the potential of compounds to activate both wt- and mutated (G551D and delF508) CFTR. Three sources of molecules can be used: synthesised

compounds, chemical libraries or natural product. The selection of HITs is performed using an automated cell-based radioisotope primary assay. The ability of small molecules (Becq et al., 1999, Bulteau et al., 2000) to selectively activate wt-CFTR, G551D and delF508 CFTR chloride channels is determined. Secondary assays are then performed using electrophysiological methods and confocal imaging to study export of delF508 from the ER in cystic fibrosis cells. MPB-07 and MPB-91 corrected the delF508 activity through facilitation of its processing in airway and pancreatic duct CF cells. Selected compounds having the best activity are also submitted to primary safety evaluation. Using such methodologies, we demonstrated the low toxicity of MPB-07, -27 or -91 at doses that activate normal and mutated CFTR which confirm their great interest for the pharmacotherapy of CF.
Supported by AFLM, CNRS and ANVAR.

ACTIVITIES OF THE NATIONAL CF CENTER IN PRAGUE: INTEGRATED CARE FOR CF PATIENTS IN THE CZECH REPUBLIC

M. Macek Jr., A. Krebsová, M. Koudová, R. Alánová, E. Hladíková, M. Macek, D. Zemková, V. Vávrová
CF Center Charles University- II. School of Medicine & UH Motol, Prague, Czech Rep.

The Czech Natl. Center for Diagnosis & Treatment of CF (CZCFC) was established in 1997 (www.lf2.cuni.cz/ustavy/ublg/e_cf.html
CZCFC comprises Clinical- and Genetics Units. The Clinical part is affiliated with the European CF Soc. (ECFS; www.uwcm.ac.uk/uwcm/ecfs/intro.html), while the Genetics Unit is a part of the Czech DNA laboratories registry (CZDDNAL; www.uhkt.cz/1250/forms/dnaform sqw), that is closely linked to the EMQ Network (www.emqn.org). Integrated team of nurses, technicians, pediatric & adult pulmonologists/gastroenterologists, med. geneticists/counsellors, andrologists, gynaecologists, anthropometrists and physiotherapists provides comprehensive dg./clin. services. The objectively established incidence of CF in our country is 1 in 2800 newborns. The CZCFC has been providing specialised care to 312 patients (pts), who represent ~76 % (312/411) of all known cases in our country. We strive to examine all known cases in our country at least once a year at CZCFC. Due to long-term follow-up, longitudinal clinical / anthropometric data from all pts, treated at CZCFC since 1968, have been entered into a database. Our sweat testing laboratory has experience with over 23 000 tests. Socio-economic changes during the last decade enabled substantial progress in CF treatment, thus providing a unique chance to assess the influence of modern therapies. The Genetics unit provides comprehensive prenatal- / postnatal diagnostic services at a dg. turn-around time of ~10 days. We have implemented a "cascade screening" protocol for the most common *CFTR* gene mutations (Med. Genetik 9:158; P4.319) by initially testing for the D F508 followed by using the Research Prototype Assay from Roche Mol. Systems (D F508**,** D I507, G551D, G542X, N1303K, 1717-1 G->A, W1282X, R553X, R347P, R334W, 3849+10kb C->T, R117H, 621+1G->T, A455E, S549N, R560T, 5/7/9T-IVS 8), including 1898+1 G->A and testing for Slavic CF alleles: CFTRdele2,3(21kb) and 2143delT. These CF alleles account for > 94% of all mutations in our population. Prenatal genetic services are complemented by cytogenetic, ultrasound and biochemical exams. We also test for *CFTR* gene mutations in chr. idiopathic and hereditary forms of pancreatitis, obstructive - / non-obstructive male infertility. At our website we provide information for physicians and CF families and we closely collaborate with the Czech CF patient support group (freeweb.coco.cz/CF). Finally, we also serve as an EU accredited Marie Curie Training site for CF mutation detection. Since 1997 we provide internal EQA schemes for six additional laboratories performing *CFTR* gene mutation screening in the Czech/Slovak reps. within the frame of CZDDNAL. Having repeatedly passed the European CF Network EQA scheme (www.kuleuven.ac.be/cme/cf/) we apply its "once a year" model to our collaborating laboratories. In this respect we have a very positive mutual experience that led to improved CF diagnostics in the entire country.
Supported by MSMT: OK 192, ME258; CIG-LN00A079, 111300003 and MZ CR: 00000064203.

ABOUT HUMAN GENETICS AND HUMAN BEINGS

The position of patients in the decision process in scientific research

H. Weggen
ICF(M)A

What should be the focus of scientists in Human Genetics? The direct results of their projects or the effects of their research on the lives of human beings. Of course, in the first place the human beings they work for, because the results of the work done can have huge consequences for them. At this moment you can question if this is their focus. Do patients play a role in choices made in human genetic research? At this moment we must say no, patients have no role.
So the time has come that patients should play a role. But is that a realistic and attainable view? Realistic in the way that we consider it possible that patients are equal partners. To find this out it is necessary that we know what knowledge and skills are needed. We consider it possible that from all the interest groups, the group of patients can make a most valuable contribution by stating its point of view.

WHY SCREEN FOR CYSTIC FIBROSIS?

J.A. Dodge
Department of Child Health, Singleton Hospital, Swansea, Wales, UK

Cystic fibrosis (CF) is relatively common, serious, and causes lung damage. Clinical diagnosis is usually associated with malnutrition which may take up to 2 years to correct. Clinical diagnosis may also be delayed until lung damage has occurred, and infection may start as early as 6 weeks of life. A well organised screening programme should identify the great majority of affected infants within the first 3 weeks after birth, which leaves a possible small time window during which effective preventive treatment and surveillance may be instituted. Active treatment, whether for screened or unscreened infants, improves clinical status and long-term survival of CF-patients. It is anticipated that new treatments will become available within the next few years, and these will clearly give maximal benefit to young infants if instituted before lung damage is evident. In addition to any hypothetical effects on morbidity and survival, pre-symptomatic diagnosis greatly improves the doctor-parent relationship. Economic arguments may be distorted, but, at best, screening is cost-beneficial, and, at worst, it is cost-neutral. The overwhelming majority of CF professionals and parents universally support neonatal screening, so the onus is therefore on those who oppose screening to prove that their approach offers a superior strategy.

The next annual symposium of the CF network is foreseen at the 25th European CF-conference in Genova 17-23 June 2002.

Els Dequeker, Leuven, Belgium

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REPORT TRAINING

Laurent Doucet, MD pathologist, Laboratoire de Biogénétique, Brest, France, under supervision of Prof. Claude Férec, visited the Cystic Fibrosis Research Group, headed by Prof. Margarida Amaral and Dr. Deborah Penque, Centro de Genética Humana, Instituto Nacional de Saúde Dr Ricardo Jorge, Lisboa, Portugal, between 4th February and 1st April 2001.
The purpose of the visit was to test different conditions for an immunohistochemical approach to localize CFTR in human native tissues by a large panel of CFTR antibodies.
This work was partly presented at the Second Consensus Meeting Towards Validation of CFTR Gene Expression and Functional Assays, 30th March - 1st April 2001, in Estoril (Portugal).
Depending on the conditions used to collect the samples, which may dramatically influence the preservation of tissue morphology, this technique allows the precise localisation of the CFTR protein in human or model animal samples. By using double-staining, the technique also enables the detection on the same sample of various other markers (*e.g.*, those for differentiation).

Laurent Doucet and Claude Férec, Brest, France
Filipa Mendes, Deborah Penque and Margarida Amaral, Lisboa, Portugal

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ANNOUNCEMENTS

Second meeting with the Industry
6 November, 2001 - Brussels, Belgium,

A second information meeting with the industry will be organised in Brussels on 6 November, 2001. The CF network is interested in discussing with representatives of the industry, issues pertaining to different aspects of CF diagnosis, treatment and research, such as the production of diagnostics or new therapeutics, but also the more basic aspects of CF research.

Invitation letters were sent earlier and the following companies already confirmed their attendance: Applied Biosystems, Astra Zeneca Diagnostics, Genzyme, Ingeny International BV, Innogenetics and Savyon Diagnostics Ltd.

If you are aware of someone in the industry that would also be interested in our CF network, or if you are a representative of a diagnostic or therapeutic industry yourself, please contact
Prof. Jean-Jacques Cassiman or Dr. Els Dequeker,
tel. 32-16-34 58 60, fax 32-16-34 59 97,
CF.network@med.kuleuven.ac.be.

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2001 CF Quality assessment scheme

The deadline for registration for the QA scheme is 31 July 2001. So far 108 laboratories already made their registration for the QA scheme of 2001. Last year 191 labs participated.

The time schedule for the next CF Quality Assessment scheme is given below:

June - July 2001:
Laboratories which would like to participate and are not registered yet, please download the registration form from our website and e-mail or fax it to E. Dequeker.
Els.Dequeker@med.kuleuven.ac.be
Fax 32 16 34 59 97
September 2001:
Distribution to the registered participants of the six purified DNA samples with clinical information
December 1, 2001:
Deadline for submission of the genotype results and written reports to the coordinating center
March 2002:
Results and evaluation reports of the CF QA scheme 2001 available

For more information of the QA scheme go to our website:
http://www.cfnetwork.be/genetic_diagnostic_labs.htm

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European CF network International symposium 2001
9 - 10th November, 2001 – Tallinn, Estonia

The European CF network will organise for the fifth time a symposium for CF in East and Central Europe. This year it is planned for 9 -10th November in Tallinn - Estonia with Maris Teder and Maris Väli as local organisers.

The aim of this meeting is to bring together as much as possible scientists and clinicians involved in fundamental CF research, genetic diagnostic labs, CF associations of families and all other interested persons.

Lectures on clinical aspects, more fundamental aspects, and quality assessment on Cystic Fibrosis will be presented. We invited the companies that have a commercial kit on the market for mutation detection of CFTR mutation for a presentation of their assay. Similar to last year we will organise a poster session. We would appreciate if each participant would submit an abstract summarising his/her work on cystic fibrosis. We will publish the abstracts in a separate leaflet, and abstracts will be selected for oral presentation during this symposium.

This International Symposium is open for all people interested. Although there is no registration fee, registration should be made before September 15, 2001. Registration form and information for abstract

submission can be found on the web page of CF network: http://www.cfnetwork.be/meetings.htm.

For more information, please contact

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Herestraat 49, B-3000 Leuven - BELGIUM
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CF.network@med.kuleuven.ac.be

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Database participants of the European CF network

The European network brings together all parties involved in the common quest "the fight against CF" with the aim of making information more easily available to everybody. Therefore it is **very important that all names and affiliations of the participants of the CF network should be available on our website at** http://www.cfnetwork.be/participants/. This personal information will only be made publicly available on the internet after you signed and sent us a registration form that allows us to do so. With this message, **we would like to ask each participant to check if he / she is included in the webdatabase**. The fact that you received this Newsletter does not necessarily mean that your coordinates are also included in the database that is available on this website. If your name is not yet on the web, please go to http://www.cfnetwork.be/Registration_form_CF_Network.doc, download the form, and send or fax (32-16-34 59 97) it before September 1, 2001 so that our records can be updated.

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CFTR-gene primers for DGGE

Ingeny International offers a special price for the CF network members ordering CFTR-gene primers for DGGE. For more information see Newsletter July 2000 or contact:
Ingeny International BV
Amundsenweg 71,4462 GP Goes
The Netherlands
Tel. +31 222 920 - Fax +31 222 923
http://www.ingeny.com - e-mail: info@ingeny.com

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CONGRESSES AND MEETINGS

Under this heading we would like to inform you on congresses and meetings of interest to members of the CF network. If you organise a meeting open for the public, please inform us. We will be happy to announce your meeting via the CF network newsletter and website. Please inform us also about other interesting meetings not yet mentioned in this list.

4th Australian Cystic Fibrosis Conference
Brisbane Queensland, Australia,
23-25 August 2001
Conference office: Cystic Fibrosis Australia,
PO Box 254, North Ryde NSW 1670, Australia
or e-mail: general@cysticfibrosisaustralia.org.au

ASHG meeting
San Diego, California, U.S. - 12-16 October 2001.
Conference website:
http://www.faseb.org/genetics/ashg/meet-2001/2001meetmenu.htm

15th North American Cystic Fibrosis conference
Orlando, Florida; U.S., 25-28 October 2001
E-mail: NACFC@cff.org

5th European CF network international symposium 2001
Tallinn, Estonia, 9-10 November 2001
Meeting website: http://www.cfnetwork.be/meetings.htm
E-mail: CF.network@med.kuleuven.ac.be

3rd consensus meeting towards validation of CFTR expression and function assays
Lisbon, Portugal - 12 April 2002
Conference office: Centro de Genética Humana, Instituto Nacional de Saúde Dr. Ricardo Jorge, Avenida Padre Cruz, P-1649-016 Lisboa, Portugal
Meeting website:
http://www.cfnetwork.be/NextMeeting.htm

25th European Cystic Fibrosis Conference
Genoa, Italy - 17-23 June 2002
Conference website: http://www.ecfsoc.org
E-mail: me6244@mclink.it

26th European Cystic Fibrosis Conference
Belfast, Northern Ireland - 4-7 June 2003
Conference website: http://www.ecfsoc.org

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Cystic Fibrosis European Network

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Fax to 32 16 34 59 97 or mail before July 30, 2001

Registration form – European Quality Assessment Scheme for CF 2001

We are interested in participating in the External Quality Assessment scheme for CF organised by the CF Network in September – November 2001

Name:

Laboratory:

Address:

Country:

Tel.:

Fax:

E-mail:

We participated in the European QA scheme for CF in *

- ☐ 1996
- ☐ 1997
- ☐ 1998
- ☐ 1999
- ☐ 2000

*mark the years you participated