

CONTENTS

- * Editorial
- * Cystic Fibrosis Worldwide
Herman Weggen
- * CF-Pronet Seminar
Frauke Mekus and Stefan Wölfl
- * Workshop Verona
Pier Franco Pignatti
- * Workshop Leipzig
Manfred Stuhmann-Spangenberg
- * 6th International CF Symposium, Dubrovnik
Jean-Jacques Cassiman
- * Report training
Heather Davidson
- * Report training
Anca Dragomir
- * Announcements
- * Congresses and meetings

NEWSLETTER CONTRIBUTIONS

The closing date for the next issue of the CF Thematic Network newsletter is January 30, 2003. Please forward your data and contributions for the newsletter to:

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EDIOTRIAL

Dear friends and colleagues,

Another year is coming gradually to an end. Looking back, I am again impressed by all the activities of the Network. The different newsletters of this year, including the ones of the European Working group on CFTR expression, give only a limited overview of what the Network realized this year. Much more important is what it did to all those involved in the Network, the exchanges of scientists, the quality improvements in the services, the establishment of a true repository for methods and technologies, the interaction with the industry and last but not least the interaction with the ECFS and the patient organizations. In addition the Network was officially extended into the Newly Associated States and we will soon be able to welcome the five new official partners in the Network Steering committee.

On the 6th Framework program of the EU, the news is less good. The 'European Institute for the Diagnosis of CF and related diseases' as proposed in our expression of interest, was not retained as a priority theme for the next two calls. This means that we will not be able to propose CF as a model disease for other genetic diseases and that alternative strategies will have to be found in order to continue to build on the experience gathered during the 12 years of consecutive concerted actions and the present Thematic Network. Different suggestions have already been made, but we will have to await the definite call from the EU, on December 17th of this year, to be able to decide what strategy we will follow. I would suggest that all of you watch out for this call and if you have suggestions, to make them known to the CF community through our Network website for all to read and discuss.

(<http://www.cfnetwork.be/suggestions.htm>).

In the mean time the Network activities will of course continue at the same or even increased intensity. This coming year should in addition help us to prepare the future of the present or of similar activities. We are counting on all of you to make it a fruitful and significant milestone towards better CF management.

The snow has not yet appeared in the sky, and the New Year is still a month away, nevertheless we would already want to wish you all a successful and happy 2003.

Jean-Jacques Cassiman
Coordinator of the CF-network
Leuven, November 2002.





Cystic Fibrosis Worldwide

Merger update ICF(M)A and IACFA

The merger process between IACFA and ICF(M)A continues as both organizations agreed during the Annual Business Meeting in Genoa on June 19, 2002 the draft by-laws and incorporation papers of the new organization "Cystic Fibrosis Worldwide".

We look forward to launching the new constitution as from January 2003 that incorporates the agreements that we reached in Genoa June 19, 2002.

This conference in Genoa was a milestone for our organization as our first merger discussions started in February 1999 in Madrid. It took some years of preparation to merge but we are all convinced that we now will be able to continue our work on a worldwide mandate and to improve the fulfilling of our vision and mission.

Vision: People whose lives are affected by Cystic Fibrosis must have equal opportunities to participate in their society no matter where they live.

Mission: Promote access to appropriate care for all people with Cystic Fibrosis Act as an international platform for the exchange of information (CFW should be the first point of reference to act as a platform to exchange the information). Support the search for a cure.

Within our organization we also feel a strong need to build understanding and knowledge of CF around the world among both lay and medical communities and with government offices to improve the quality of life of patients with CF.

Regional levels

It appears that the world is too big for one policy of CFW. Problems and solutions are different in several parts of the world. For that ICF(M)A started in 2001 with a regional approach. The Executive Committee appointed regional officers with special attention for Latin America, Europe and for the Far East. New countries will be contacted by the president. For activities in these regions a budget has been allocated. The first experiences with this approach are positive. Now we made clear which person is responsible and which person our members can approach if they have a request for regional support.

For Latin America this already resulted in the FLAFQ (Federation Latin America Fibrosis Quistica). At this

moment there is an initiative to establish an European branch. We are very happy with this.

Medical advisors

For the future of CFW it is important to have access to different advisors. It is therefore suggested and decided that CFW should approach well-known advisors (being scientists, physicians, nurses) for various tasks, or a single job for a limited period on honorary basis.

CFW has to take this opportunity and this might even be a better tool to obtain more influence world-wide (e.g. WHO or on national/ governmental level).

Lay conference programme

In Genoa we also agreed that it is important to continue with the idea of a lay conference day beside the regular Annual Business Meeting. Some ideas to improve the contents are:

- Not only lectures, but
- More exchange on international level
- Exchange between CF adults (on international level)
- More attractive subjects of interest for CF adults.

Web-site / newsletter

The newsletter of IACFA has shown its necessity and without doubt needs to be continued. As always the newsletter will be packed with research information, medical news and personal experiences. Our new website will soon be official. Our webmaster is very hard working to improve the website and to update all our information. www.cfww.org

CFW office

Our office can be reached through:

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Herman Weggen, Helmond, The Netherlands



**CF-PRONET SEMINAR
JENA, SEPTEMBER 2, 2002 – SEPTEMBER 3, 2002**

Participants from CF-Pronet:
Burkhard Tümmeler, Frauke Mekus, Andrea van Barneveld; MH Hannover Larissa Pusch, Marina Pfalz; FSU Jena, Stefan Wölfl; FSU Jena and Clondiag CT Jena, Thomas Ellinger; Clondiag CT Jena

The meeting began Monday with a visit of the labs of the Molecular Biology group in the new research center of the FSU Jena Medical department and was

continued with a seminar lecture "Cystic fibrosis twins and siblings, genetic modeling and candidate gene analysis: On the relative impact of environmental and inherited modulators on cystic fibrosis disease severity" by Frauke Mekus. The lecture described the results of the European CF Twin and sibling study. She focused in particular on the variation in severity of the disease in siblings, and gave a detailed presentation of the electrophysiological phenotype. These measurements are done on rectal biopsies and provide insight into the ion channel repertoire in these biopsy samples. Presence and absence of CFTR mediated residual activity correlates with the severity of the disease.

After the seminar, the CF-Pronet researchers from Hannover (P3) and Jena (P7) discussed the present state of workpackages WP8 (recruitment of CF patients) and WP6 (transcriptome analysis). The first results of the transcriptome analysis from rectal biopsies (WP6) had been obtained. Results in this respect are that RNA samples from fresh non-frozen tissue were of better quality and that electrophysiological measurements did not significantly change the expression profile from a healthy donor sample. These results provide the basis for the next step of using sibling biopsies enrolled in the sibling study (WP8). For this study RNA will be prepared right after intestinal current measurements in Hannover by members from the Jena group. It was also discussed that the effort of WP5 (proteome analysis) should be supported with RNA/cDNA material obtained from the rectal biopsies.

On Tuesday the group from Hannover continued their visit in Jena at Clondiag CT GmbH, the SME associated with partner P7. They were informed about the production of chips for cDNA analysis and genotyping. In particular, the new array-tube platform developed at CCT that should make the array technology more easily accessible was introduced.

Frauke Mekus and Stefan Wöfl



WORKSHOP VERONA: QUALITY CONTROL IN THE GENETICS LABORATORY HELD IN VERONA, ITALY, 24 SEPTEMBER 2002

On September 24, 2002, a Workshop on Quality Control in the Genetics Laboratory was held in Verona, under the auspices of the CF Thematic Network.

The workshop was conveniently nested between a preceding meeting of the molecular genetics laboratories belonging to the Italian CF Group (GIFC), and the following annual congress of the Italian Human Genetics Society (SIGU), so that most interested individuals had several good reasons to participate. The workshop in fact numbered an unexpectedly high attendance that left people standing in the 250 seat room where it was held.

Everyone received a booklet with the workshop proceedings including the abstracts of the presentations, the list of pre-enrolled participants, the names of the sponsors and their product advertisement, the addresses of the member laboratories of the Italian CF group, and a copy of the "Recommendations in a nutshell" for CF testing (EJHG 2000; 8:S2-S24).

At the end of the workshop, the participants who wished to do so filled in a questionnaire with multiple choice answers and an evaluation sheet in order to obtain points in the now obligatory continuous education program for Italian physicians and biologists.

The workshop included 5 reports: an "Introduction" by the undersigned Pier Franco PIGNATTI (University of Verona), "the practical experience of a genetics lab in a large hospital" by Maurizio FERRARI (Milan San Raffaele Hospital), "the QA schemes and recommendations" by Els DEQUEKER (Un. Leuven), and "the OECD survey on molecular genetic testing laboratory practices results" by the two Italian representatives Giuseppe NOVELLI (Rome University Tor Vergata) and Domenica TARUSCIO (Istituto Superiore Sanità, Rome). A discussion followed.

P.F.PIGNATTI 1. summarized data on genetic testing and QC for CF in Italy, 2. discussed the question of testing for CF-related diseases, and 3. proposed the preparation of a CFTR mutation European panel.

1. The statistics on genetic tests performed in Italy in year 2000, from the data collected by the Italian Society of Human Genetics (available at the society's web site <http://sigu.univr.it>), show that CF testing is in the second position of the most performed molecular genetic tests after HLA testing. The high number of CF tests may also be due to the fact that Italy has a Law on having a CF Center in each Region for the cure of CF, and to the widespread use of the test in assisted reproduction clinics. He indicated that the major problem which emerged from the first national CF external QC was the lack of CF-residual risk calculation after mutation testing, which led to diagnostic errors as one mutation was rare, and most labs in the end diagnosed as a carrier a CF case who was a compound heterozygote with the rare mutation.
2. In the testing for CF-related diseases, disseminated bronchiectasis (DBE) and idiopathic pancreatitis (IP) were also mentioned, but due to the variety of mutations which might be present, the relative low percentage of mutation carriers, and the high gene screening costs, it was suggested to routinely test for CF gene mutations only in congenital absence of the vas deferens CAVD or artificial insemination cases and not in DBE or IP.
3. The suggestion for an European panel of mutations, with reference to the panel recently

approved in the USA, includes most of the same mutations, and others, which could be classified as "regional" mutations as they are particularly represented only in some of the European regions, and could possibly constitute additions to a "core" panel to be used throughout Europe. Further studies are needed to better determine the CF mutation frequency in some European countries for which only limited information is available.

M. FERRARI 1. indicated the quality assurance (QA) procedures in the ISO 9001-2000 norms, 2. discussed the factors that determine the accuracy of genetic testing.

1. QA needs consideration of lab organization, safety procedures, an instruction program for personnel, a continuous education program, an evaluation of the performance, test validation, and QC. The ISO norms include an evaluation of all procedures, from planning, to development, validation, and possible modifications to the method. Validation must be analytical and also clinical.
2. Accuracy depends on technology diversification, applications, regional differences, number of tests performed, standardization of single laboratory developed tests, and other factors. The necessity of a continuous education program was stressed for the continuous evolution of knowledge and of techniques, including practical training, planning of workload subdivision among operators, and filling in a check-list of objectives, tasks, timing and resources necessary. Internal QC of the instrumentation, reagents, samples, and the participation to External QC schemes are necessary. What is presently needed is the development of validated control samples, programs for performance evaluation, the activation of laboratory consortia for information exchange on specific pathologies and methods, networking of data-bases of the labs, and the improvement of professional formation and continuous education for clinicians and laboratory personnel, as data quality in the end depends on the experience and the professionalism of the operator.

G.NOVELLI indicated 1. OECD activities and the results of a pilot study in genetics in Europe, and D.TARUSCIO then reported 2. provisional results of the OECD study for Italy.

1. The Organization for Economic Cooperation and Development (OECD) presently enrolls 30 industrialized countries, which represent 2/3 of the world production of goods and services. The OECD objectives include economic development and occupation, assistance to developing countries, international commerce and exchange. OECD decided to review the current situation in genetic testing, to explore the impact of new technologies upon healthcare practice, to consider the impact of commercialization of new genetic technologies on healthcare economics, make policy statements on

best practice, and stimulate international harmonization of genetic testing. A pilot study was proposed in order to collect data on the current status of quality assurance practices in genetic laboratories. It received 155 completed surveys, which are being analyzed at present in more detail. Available data indicate that 54% of the respondents are located in public hospitals. Of the responders, 86% diagnose monogenic disorders, 43% offer presymptomatic testing, 41% predisposition testing, and 5% pharmacogenetic testing. Mutation detection is offered for 86 different single gene disorders. The total number of tests performed in year 2001 is 450.000.

2. In Italy, the questionnaire was sent to 140 laboratories selected from the Italian Society of Human Genetics list (web site is given above), and 70 public plus 6 private laboratories replied with a completed questionnaire. Genetic counselling was offered by lab-affiliated physicians in about 85% of cases. Informed consent was required in about 75% of the tests. The data so far analysed in the pilot study for Italy produced in general similar results as the other countries in the OECD study.

E.DEQUEKER 1. reviewed the European EQA schemes for CF, and focussed on 2. the genotyping and reporting errors.

1. Six European CF-EQAs were performed yearly from 1996 to 2001, and the seventh is presently ongoing. They were sponsored by the Biomed 2 program for the first three years, then by the European CF Network. Each lab received 6 blinded DNA samples and an accompanying letter of request and was asked to genotype for CFTR gene mutations using its routine protocol.
2. The percentage of correct genotyping increased from about 65% in 1996 to about 90% in 1999,2000,2001. Learnings for the EQA schemes: sample mix up can occur in every step of the procedure, genotyping errors may be due to the method applied. A tendency to use commercially available kits for primary testing was clear. In year 2000, 47% of the errors were technical, 32% were misinterpretations of technically correct results, and 21% were administrative errors. The errors were not limited to a small percentage of labs, but were disseminated among many different labs. There was a large variation in the written report format among different labs, and 39% submitted a report with a mistake in year 2000. These reporting errors were largely administrative (77%), less in the interpretation of results (15%) and fewer still in risk calculation (8% in 2000, down from 25% in 1999). The recommendations for quality improvement in genetic testing for CF which were derived from this experience were published as given above, and are available in the CF Network web site in PDF file format at: <http://www.cfnetwork.be/manuscript.htm>.

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REPORT ON THE WORKSHOP „MOLECULAR GENETIC DIAGNOSTICS OF CYSTIC FIBROSIS“ (LEIPZIG, SEPTEMBER 28 TO 29, 2002)

Until now, three workshops „Molecular genetic diagnostics of Cystic Fibrosis“ have been organised in Germany: In Hannover (1997), Lübeck (2000) and now in Leipzig. 42 participants from German, Swiss and Belgian labs attended the latest workshop. This workshop was a Satellite workshop of the 13th Annual meeting of the German Society of Human Genetics and included practical work as well as lectures.

The practical work included CFTR mutation analysis in 5 different DNA samples with known mutations. All DNAs were tested with the following methods:

PCR/OLA (Applied Biosystems)

PCR/DNA Line Probe Assay (Innogenetics)

PCR/ARMS (Orchid Diagnostics)

PCR/SPOLA (Variom)

PCR/WAVE (Transgenomics)

In most cases, the participants were able to identify the correct CFTR genotypes of the DNA samples. Most methods were performed without any problems. In two cases, mutations were missed, most likely because of pipetting errors and/or wrong running conditions.

The practical work was accompanied by lectures on the methods used, given by representatives from the 5 companies mentioned above as well as from Nanogen (Chip technology). In addition, B. Pabst from Hannover presented a lecture on CFTR mutations in different populations, interpretation of results and risk calculation. D. Gläser from Neu-Ulm and Ch. Aulehla-Scholz from Stuttgart presented results from diagnostic sequencing the entire CFTR gene and discussed the indications and limitations of this method as a diagnostic tool. Last but not least, E. Dequeker from Leuven gave an excellent overview on Quality assessment for genetic testing for cystic fibrosis.

The workshop offered a very good opportunity for the participants to become an overview about currently used mutation detection methods, namely

commercially available ones. The combination of practical work and lectures about the theoretical background was very well acknowledged by the participants. A special thank goes to the members from the Institute of Human Genetics in Leipzig for their never ending patience and hospitality.

With the support from the CF European network and the 6 industrial companies mentioned above it was possible to produce a workshop proceedings booklet. Anyone who is interested to receive a copy of this booklet, which contains articles in German and English, is kindly requested to contact E. Dequeker or M. Stuhmann-Spangenberg (stuhmann.manfred@mh-hannover.de).

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THE 6TH INTERNATIONAL SYMPOSIUM ON CYSTIC FIBROSIS. SATURDAY, NOVEMBER 2, 2002, DUBROVNIK, CROATIA

As in the past, the Thematic Network on CF organized, with the benevolent help of scientists from Zagreb, an interdisciplinary meeting on Cystic Fibrosis for scientists and clinicians from eastern and central European countries. The general idea is to invite a limited number of international experts to give a presentation on a specific topic of importance to clinical management or molecular diagnosis CF as well as research topics. In addition, the participants had the opportunity to share and discuss their experience in the management of CF through an oral or a poster presentation.

43 participants representing 19 different countries attended the meeting actively. While the sun was shining outside and people were swimming, we listened to 6 invited speakers (each 30 min) and to 20 oral presentations (each 10 min), interrupted by a short but very pleasant lunch. The topics of the presentations varied from the patient care in the different countries, over difficulties in confirming the diagnosis, the management of centers for adult patients, the frequency of the mutations in different countries and new methods for the detection of Burkholderia Cepacia. At the end of the meeting the 20 posters, displayed in an adjoining room, were actively viewed and discussed. The meeting was formally closed at the end of a well-deserved dinner. The abstracts of the meeting will be available soon on the <http://www.cfnetwork.be> website.

The participants, including a significant proportion of students, both pre- and postdoc, insisted on the

importance of these meetings for them and requested that this tradition should be continued next year. A time and place for the meeting will have to be decided in the future. Suggestions are welcome.

JJ Cassiman, November 6th, 2002

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REPORT TRAINING

VISIT CYSTIC FIBROSIS RESEARCH LABORATORY, LISBON

Heather Davidson, research scientist in the Cystic Fibrosis Gene Therapy Group, headed by Dr. Chris Boyd, in the Medical Genetics Section, headed by Prof. David Porteous, of Edinburgh University, visited the Cystic Fibrosis Research Laboratory, headed by Dr. Deborah Penque and Prof Margarida Amaral, Centro de Genetica Humana, Instituto Nacional de Saude Dr. Ricardo Jorge, Lisboa, Portugal, between 6th July and 3rd August 2002. The purpose of the visit was to gain experience in immunocytochemistry using a panel of human CFTR antibodies. The Edinburgh team is now collaborating closely with groups in Oxford and London in the UK CF Trust funded CF Gene Therapy Consortium (<http://www.cfgenetherapy.org.uk/>) and as part of the Consortium is involved in verification of the sheep as a model for CF gene therapy. Additionally, experiments evaluating human nasal epithelium from normal and CF individuals similar to that done by Penque et al (Lab Invest 2000, 80:857-868) were performed and invaluable expertise was gained in the use and interpretation of human CFTR antibodies.

Immunocytochemistry techniques were carried out on sheep ALI (air liquid interface) cultures of primary tracheal epithelial cells to further verify this system as an ex vivo model for evaluating gene therapy formulations and vectors. Parallel experiments on human and sheep nasal epithelial cells were also performed. Interestingly, initial results showed that while some human antibodies were able to detect sheep CFTR, others were negative. These findings will form the basis of further experiments to be carried out in Edinburgh. In addition, immunocytochemistry of CFTR antibodies to cryosections of transgenic mice lungs carrying a human genomic CFTR transgene should inform us on the pattern of expression it confers.

The expertise gained from the visit has been invaluable and will form an essential part of our gene therapy research programme.

Heather Davidson, University of Edinburgh, Edinburgh, United Kingdom

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VISIT LABORATORY OF MEDICAL BIOCHEMISTRY, CARDIFF

Visit of Anca Dragomir, Ph.D. student under the supervision of Professor Godfried Roomans, Dept. of Medical Cell Biology, Uppsala University, Sweden, to the laboratory of Drs. R.L. Dormer & M.A. McPherson, Dept. of Medical Biochemistry, University of Wales College of Medicine, Cardiff, UK (28th July – 1st August, 2002)

The purpose of the visit was to exchange technology and to compare and harmonise protocols for preparing nasal epithelial cells obtained by brushing for measurement of CFTR Cl⁻ transport using the MQAE fluorescent dye and for immunolocalisation of CFTR.

Two methods for obtaining nasal cells by brushing were compared. Using a harder interdental brush (Uppsala method), large numbers of cells were obtained that were usually in clusters and contained both ciliated and non-ciliated cells. With the softer brush (Cardiff method) smaller numbers of cells were isolated but were almost 100% ciliated. The viability of the cells using both methods was very good. No bleeding or persisting pain was observed with either technique but the softer brush may be better tolerated by CF patients.

A consensus protocol was obtained for loading cells with MQAE and sticking them onto Cell-Tak coated coverslips. An important modification (Uppsala method), to pre-treat coverslips with 5N HCl for 30min before washing and treating with Cell-Tak, was found to be necessary for cells to remain in place in long-term Cl⁻ transport experiments. Several cell lines (Calu-3, IB-3, transfected HEK cells) were also compared and again, consensus techniques were obtained for handling and preparing the cells for chloride measurement.

Using the equipment available in Cardiff, it was observed that the MQAE fluorescence in cells did not respond to agonists or changes in external Cl⁻ concentration. Control experiments in a spectrophotometer cuvette showed that MQAE in a salt solution and in loaded cells exhibited the specific MQAE emission spectra, with a maximum at 460nm. An extensive comparison of instrumentation for fluorescence measurements was carried out and potentially key differences identified; a) Cl⁻ measurement was from cells in a droplet, as previously used extensively for intracellular Ca²⁺ measurements (Cardiff) or in a perfusion system (Uppsala); b) a shutter for the monochromator such that cells are exposed to UV light for only 16 ms at every 3-6 second interval (Uppsala) was not present in Cardiff but this was not perceived to be a problem since the MQAE fluorescence was stable over a long time and the cells were not affected; c) for measurement of emitted light a barrier filter centred at 460 nm with 30 nm bandwidth (Uppsala) compared to a filter that allows light of longer wavelength to pass

(Cardiff). Further experiments in Uppsala using Cardiff cells and modifications being made to the Cardiff instrument will confirm the importance of these differences.

An exchange of protocols and tips for immune staining of CFTR also took place. Using a consensus protocol (Cardiff) in Uppsala resulted in much better staining of CFTR in cells being obtained.

A future more detailed report will be submitted to the Virtual Repository as an addendum to the current protocols to aid other workers who might wish to set up these techniques.

Anca Dragomir & Godfried Roomans, Uppsala, Sweden
Bob Dormer, Maggie McPherson & Ceinwen Harris, Cardiff, UK

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ANNOUNCEMENTS

CFTR MUTATION F834L

The DNA laboratory of the Department of Clinical Genetics and Human Genetics of the VU University Medical Center, performed CFTR mutation analysis in the partner of a CFTR dF508 mutation carrier. With denaturing gradient gelelectroforese the CFTR mutation: F834L was found in this partner. This mutation was found in the Netherlands only once before The patient concerned had CBAVD; besides the F834L mutation he had a rare splice site mutation. Despite attempts to gather information about the F834 L mutation via members of the European CF network, we have no more data about this mutation. Anyone who has more information about the F834L mutation is invited to contact the department of Clinical genetics and human genetics of the VU University Medical Centre, mentioned underneath. There is special interest in the phenotype that can be expected with genotype F834L/ dF508.

On behalf of professor LP ten Kate,
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CF EXTERNAL QUALITY ASSESSMENT SCHEME 2002

Deadline December 10, 2002

Deadline for submission of the genotype results and written reports to the coordinating center:

Prof. Els Dequeker
Department Human Genetics
University of Leuven - Campus Gasthuisberg
Herestraat 49 - B-3000 Leuven
Belgium

May 2003
Results and evaluation reports of the CF QA scheme 2002 available.

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THIRD MEETING WITH THE INDUSTRY NOVEMBER 26, 2002 – BRUSSELS, BELGIUM

A third information meeting with the industry will be organised in Brussels on November 26, 2002 at the Sheraton Brussels airport (located just at the opposite side of the road next to departures and arrivals).

Program:

1. Overview activities of the EU-CF Network 2001-2002 (J.J. Cassiman, E. Dequeker)
2. Report of the Genoa WHO meeting "World Wide Molecular Genetic Epidemiology of Cystic Fibrosis" (H. Cuppens, M. Macek Jr.)
3. "Rethinking Gene Patents" (G. Van Overwalle)
4. "Guidelines for genetic testing" (H. Nys)
5. 6th Framework (J.J. Cassiman)
6. Varia (J.J. Cassiman, E. Dequeker)

Please contact Claudia Vits in case you are interested to participate, tel. 32-16-34-58-72, Claudia.Vits@med.kuleuven.ac.be.

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MANUAL FOR CF PATIENTS AND FAMILY

A manual for CF patients and family is available in English, French, German, Italian, Spanish, Czech and Slovak. Recently the manual has also been made available in Croatian, Ukrainian, Latvian, Serbian and Russian. The following languages will be available in the near future: Polish, Macedonian, Hungarian and Lithuanian. All languages can be downloaded as a pdf file from the CF network website (<http://www.cfnetwork.be/Informationdocuments.htm>) The manual includes the following topics:

- what is cystic fibrosis
- what happens in the lungs
- what happens in the pancreas
- when to suspect cystic fibrosis
- how is cystic fibrosis inherited from the parents
- to have a child with CF ... and to accept a child with CF
- treatment of cystic fibrosis
- hospital

- relatives and friends
- you are not alone



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



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.

European Human Genetics Conference, Birmingham, U.K., 3-6 May 2003
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26th European Cystic Fibrosis Conference Belfast, Northern Ireland, - 4-7 June 2003
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