

## Uafhængig ekspert review af de to danske cystisk fibrosecentre



### Kick-off møde i København

mandag den 2. februar 2009 kl. 10.00 - 13.00

på Rigshospitalet, opgang 52, (den røde bygning), 2. sal,  
mødelokale AB2.

Dato : 18.12.2008

Journalnr. : 2-52-16-05

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Side 1/1

### Dagsorden:

1. Velkomst og introduktion af deltagerne
2. Baggrund for mødet
3. Fremlægelse af data fra de to centre
4. Præsentation af spørgsmål, som reviewet forventes at skulle besvare
5. Diskussion af mulighederne for resultatopfyldelse
6. Fastlæggelse af mål og midler for reviewet
7. Diskusssion af commitment til resultatet af reviewet
8. Afslutning + frokost

**Minutes of meeting on 2 February 2009 concerning review of the cystic fibrosis centers in Aarhus and Copenhagen, Denmark.**

**Present:**

Birgitta Strandvik, University of Gothenburg, Sweden  
Lone de Neergaard, the Danish National Board of Health,  
Susanne Vest, the Danish National Board of Health,  
Jannik Hilsted, Rigshospitalet, Copenhagen University Hospital  
Kristjar Skajaa, Aarhus University Hospital, Skejby  
Oluf Schiøtz, Aarhus University Hospital, Skejby  
Tanja Pressler, Rigshospitalet, Copenhagen University Hospital  
Hanne Wendel Tybkjær and Erik Wendel, Danish Cystic Fibrosis Association

Date : 10 February 2009  
File no. : 2-52-16-05  
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Page 1/2

**Absence with apology:**

Stuart Elborn, Belfast City Hospital, Northern Ireland

Lone de Neergaard, the Danish National Board of Health, chaired the meeting.

The background for the meeting and the external review of the two Danish cystic fibrosis centers was briefly presented.

The two cystic fibrosis centers briefly presented their explanations to the differences between the two centers.

**Decisions:**

1. The Danish National Board of Health formulates the questions to be answered by the review and forward these in writing to the two reviewers.
2. The two centers make sure that all data from the annual report for 2006-2008 are entered in the database in order to report these data to the two reviewers. This must be done by the end of March 2009. If necessary, the hospital managements will allocate the necessary resources.

3. All written instructions from the two centers are translated into English and forwarded to the two reviewers. The translation will be made by translator employed at Aarhus University Hospital, Skejby. The payment for the translation will be shared equally between the two hospitals. Translations must be finalized by the end of March 2009.

4. The two centers draft a description of the total "set-up" of their center in English and forward this to the two reviewers by the end of March 2009.

5. The two reviewers conduct on-site visits at the two centers during the review period. Relevant patient records are translated if necessary and an English interpreter will be present during the visit.

6. The review process will be finished by the end of August 2009.

7. All parties involved are committed to the result of the review and will comply with the recommendations/guidelines concerning treatment of cystic fibrosis patients resulting from the review.

8. Professor Strandvik will shortly contact professor Stuart Elborn and acquaint him with the issue. Together they draft a work plan and a time table for the review process. Professor Stuart Elborn will receive a copy of these minutes.

9. Contact persons are Kristjar Skajaa and his secretary Marianne Budde, Aarhus University Hospital, Skejby

Kristjar Skajaa  
Medical director, Aarhus University Hospital, Skejby