

ECORN-CF: A Résumé from a Patient's Perspective

by Birgit Dembski

I would like to use this opportunity to draw some conclusions on ECORN-CF from a patient's view after this project has been running for almost three years.

ECORN-CF certainly is a great project and offers patients and families to obtain

- a quality-checked second opinion
- quality-checked information on difficult medical and scientific questions which require excellent competence

ECORN-CF

- points to topics patients are especially interested in
- enhances the collaboration between experts in quality meetings and consensus compilation
- is a source of quality-checked information for care givers

Patients and families have good reasons to be grateful for the time and resources experts from the contributing countries are investing in this project.

But will ECORN-CF be able to thoroughly improve CF care and treatment in those countries

- where the standard is still quite low

- where there is little awareness of the patients' special needs
- where the national health budget is small for economic reasons
- where CF families are isolated from each other and scattered all over the country
- where there is hardly any



specialized CF care at all?

Consider, for example, the feedback to the patient/family questionnaire from one of the countries that have participated in the ECORN-CF project: "Toby was included on the list of drugs which are reimbursed 100% by the Ministry of Health. (...) Unfortunately (...) it is expected that the money allocated this year for the national health programs will end already in June/July. (...) We started applying for supplemental funds for cystic fibrosis pro-

gram, but chances are relatively small."

What will families or patients do in such a case? How can a European Expert Advice help in such a situation?

Frankly, I personally do not expect ECORN-CF to come up with the money but I

believe in the power of knowledge: spread the information and empower the care team members and patients to know what is needed and what is considered best care. This will be the best way to put pressure on national and European authorities to fulfill the promise of the European Union:

Equal rights and opportunities – this includes health care – for all citizens of all member states.

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