

ECORN-CF - Second Opinion in CF

by Prof. Dr. T.O.F. Wagner

More and more patients look for a second opinion concerning their chronic disease – this is of course not specific to Cystic fibrosis. The efforts and resources going into this medical self-assurance are significant on both the patients' and the care teams' sides.

When we started ECORN-CF, we had the idea of spreading the knowledge and expertise about Cystic Fibrosis care throughout the European Union. We have come to learn that this is not a one-way street of delivering information but that we must be ready to learn from the best, irrespective of where they may be found. Although we do not have an extensive benchmarking process in place, we can be certain that every partner has taken his advantage from the project.

This has come true for patients who did get a chance of receiving an answer to their questions, and some have realized that the an-

swer given in the first place was not the best possible answer and could be improved – and has been improved since then: this shows to the patient not the weakness of some expert not being able to respond but the strength of admit-



ting that there may be someone knowing more or better.

The doctors involved have been pushed to their capabilities since they certainly do not want to be the ones who had to admit that there was someone spending more effort or expertise on answering the question exactly. I have made the experience that giving advice in this written form – knowing I will be checked by other experts – motivates me to be precise

and comprehensive; and yet, I have had some comments on my answers that I did learn a lot from – and I changed the answers accordingly.

As far as the topic of 'second opinion' is concerned, it seems likely that some patients have used the ECORN-CF expert advice as a means to get some further information, some more detailed thinking, and in many cases a second opinion to better understand their situation.

Again we like to stress that such Expert Advice on the net cannot replace patient doctor interaction, but it certainly gives a second view on the problems patients have to face.

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