

Foreign people and access to medical care

Panel Discussion
Nsig – ECFS 2025

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Case 1: patient S

- Male, 31 year
- Homozygous delta F508
- Pancreas insufficient
- Study Maastricht since Sept 2023
- In home country no Kaftrio available
- FEV1 before start Kaftrio: 68%
- Start Kaftrio February 2024 (after long negotiation student-insurance)
- FEV1 after 1 month Kaftrio: 82%
- Exacerbations: hard to judge

- Regular complaints for night sweats and chills
- Hospital admission due to pulmonary embolism
- Rash
- Depression? Little social contact, family in home country
- Cultural difference
- Prospects?

Case 1: Proposition

- How far do we go in negotiation with insurance?
- Depression: is this Kaftrio side effect or social circumstances?
- Cultural differences of expectation: CF team has to resolve all the problems, patient can wait and see?

Case 2: challenges

- Girl, 14 years of age
- Homozygous dF508
- FEV1: 86 %
- Frequently hemoptysis
- On holiday with her mom at her aunt who lives in our country, currently on a tourist visum

- Situation:
 - The home country has no access to modulators
 - The home country is not at war. No refugee status.
- Questions from the parents:
- Can we start with modulators while we are in your country?

- What we have done:
 - Health insurance arrangement through the mutual of the aunt
 - Admission to the hospital for pulmonary embolization
 - Review nebulization material
 - Treatment plan physiotherapy and home medication
 - For now, wait to start modulators due to a limited residence permit.

Case 2: Critical considerations

- Still start up with modulators?
- What if the tourist visa is not extended? Then there is no further access to modulators...
- Cultural differences and expectations?

Casus 3: foreign people ~ medical care

- 26 year old woman
- Mutations: N1303K – G85E
- Meconium ileus at birth
- CFRD (HbA1c 9,7%)
- CFRLD
- Repeated cholangitis and DIOS
- Enteral tube feeding (BMI 16,2kg/m²)
- Multiresistent Burkholderia Cenocepacia
- LF +/- 20% pre-tx

- Refugee status : temporary residence permit – medical need
 - Home country has no access to modulators
 - Home country is in war
 - limited social network
 - Referral 2021
 - Lung-liver TX 05/2022
 - Admission hospital 04/2022 – 11/2022
 - March 2024: refusal residence permit medical need
 - > appeal > during appeal proceedings: medical care is reimbursed.
 - > 04/2025: refusal is destroyed, new application for residence permit
- Difficulties: language barrier, anxiety, few contacts

- Was it good to do the TX? Are we keeping her dependent on our country?
In home country no experience with TX. No possible return.
- Is LTX basic medical care?
- What if the application for residence permit is refused again?
- Refugee status brings a lot of paperwork > is it the job of CFteam? (cultural differences, languages, ..)

- What is necessary medical care?
- How much medical care can you give if it's uncertain if the patient will get a residence permit?
- Is it ethical to start a (expensive) treatment which can't be continued in the home country?
- Cultural differences and expectations: impact on care?

- FINAL REFLECTIONS, CONCLUSIONS

Evaluation form NSiG Day, 4th of June 2025, Milan

