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Cystic Fibrosis Care in Germany

Melanie Graff
CF Nurse Specialist
Children Hospital Worms
Germany



www.muko.info/adressen



8000 People with CF

National Registry has data collected for 6648 Patients

88 CF-Centers

In the year 2020:
195 New diagnoses

63% via newborn screening

Newborn Screening since 2016
all over Germany



<https://www.muko.info/informieren/ueber-die-erkrankung/diagnostik/neugeborenen-screening>

Structure of Care

Yearly Appointment Outpatient Clinic

- Laboratory: Blood and microbiological test
- Pulmonary function measurement
- Imaging: Thorax, Abdomen, Bone density measurement
- Physiotherapy
- Nutritional Therapy
- Anxiety and depression Screening

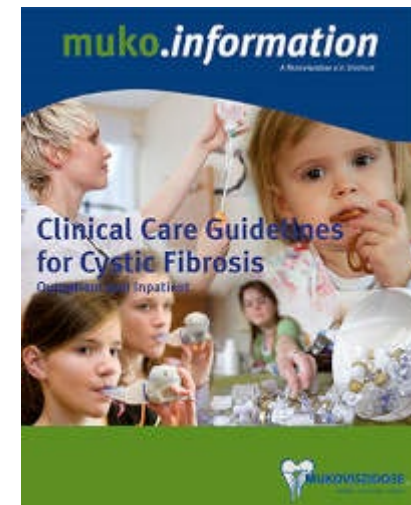
Our Patients come at least once a year up to quarterly into the outpatient clinic



National Special Nursing Group



- ❖ Since 1997 we meet twice a year
- ❖ To advance education and clinical skills for the improvement of cystic fibrosis nursing and care
- ❖ To review and update the clinical care guidelines



Nursing Research in Germany

- ❖ There is very little research in Germany
- ❖ Lack of corresponding positions in the clinics
- ❖ The only little pronounced insight of those responsible for the necessity
- ❖ Poor framework conditions inhibit the establishment
- ❖ The federal ministry of Education and Research set up a funding measure for nursing research in 2021





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Thank you very much for your attention