

## CF-CTN Germany

Cystic Fibrosis Clinical Trial Network Germany

- **Is your company planning to conduct a clinical trial in the field of cystic fibrosis (CF) in Germany?**
- **Are you a cystic fibrosis patient interested in participating in a clinical trial?**
- **Or would you simply like to receive information about cystic fibrosis research in Germany?**

### Contact us!

CF-CTN Germany is a network of qualified CF-centres committed to conduct clinical trials in Cystic Fibrosis. The network is coordinated by the scientific arm of the German CF patient association Mukoviszidose Institut (MI):

#### CF-CTN Germany Coordination Team

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### Mukoviszidose Institute (MI) - your professional partner

MI is a non-for-profit organisation registered as a charity in Germany and a 100% subsidiary of the German CF association (Mukoviszidose e.V.).

MI provides professional support and coordination in the field of scientific research and clinical trials. MI acts as the contact point and the coordinating site for the CF-CTN Germany.

Beside this, MI is maintaining and coordinating a patient registry with more than 8000 cystic fibrosis patients (please see figure). Medical Data are basis of a benchmarking project aiming at “learning from the best” to constantly improve performance of the clinics for the benefit of the patients. A compliance program for CF centers “MUKO.zert” grants a certificate to any clinical site which proves to fulfil *a priori* determined national and international guidelines of CF care.

### Age structure German CF-patients

according to the German registry. For more information please refer to:

[https://muko.info/fileadmin/redaktion/datei\\_gruppen/muko\\_institut/Regis-ter/Berichtsbaende/German\\_CF-Registry\\_Annual\\_Report\\_2015.pdf](https://muko.info/fileadmin/redaktion/datei_gruppen/muko_institut/Regis-ter/Berichtsbaende/German_CF-Registry_Annual_Report_2015.pdf)

### Age structure

The proportion of adult patients (≥ 18 years) comes to 56.5%. In 2015, no gender was recorded for one patient.

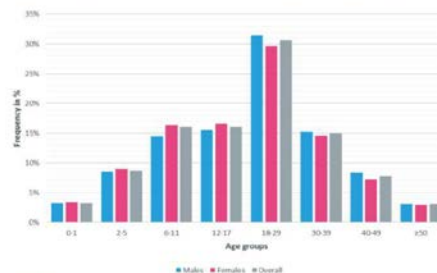


Figure 1: Age distribution, 2015

### **The German CF-Clinical Trial Network (CF-CTN Germany)**

CF-CTN Germany is a network of qualified CF-centres committed to conduct clinical trials in CF in full compliance with regulatory guidelines. While legally independent, the members have agreed to closely collaborate when preparing and conducting multicenter clinical trials in CF.

#### **Objectives:**

- Professional coordination to promote Germany as a location for both Investigator Initiated Trials (IITs) and commercial clinical trials in cystic fibrosis
- Enabling patients to get access to innovative therapies in the clinical study setting
- Working on scientific information to make it generally understandable
- Involving the patients' perspective into study set up and conduct

#### **CF CTN-sites**

- MI is the scientific office and central coordination of CF-CTN Germany ensuring that the following quality criteria are continuously met for all member sites:
- The site is certified according to MUKO.zert compliance program
- The site takes medical care of a minimum of 75 patients (children and/or adults).
- The site management can prove at least 5 continuous years of experience in the field of clinical research.
- All staff involved in the trials has received ongoing clinical training (GCP and others).
- A qualified study nurse is available at the site.

In September 2017, 23 clinical trial sites are member of the network covering more than 3.000 cystic fibrosis patients, both children and adults. In addition, there are 8 equally experienced sites working closely together with CF-CTN Germany as satellites (partner sites).

#### **Services offered by CF-CTN Germany:**

- Expert Review of Clinical Study Protocol or Patient Information
- Budget calculation for reimbursement of Study centers
- Additional services as agreed on individually

A fee listing is available on our website:

[https://muko.info/fileadmin/redaktion/datei\\_gruppen/muko\\_institut/CTN/Fees\\_CFCTN\\_2017.pdf](https://muko.info/fileadmin/redaktion/datei_gruppen/muko_institut/CTN/Fees_CFCTN_2017.pdf)

#### **Cooperation with International Networks**

As Cystic fibrosis is a rare disease, international cooperation is crucial for the success of clinical trials, to enable an efficient recruitment of patients and to provide standardized techniques and methods. Therefore, MI as well as CF-CTN Germany is cooperating closely with international networks and organizations, such as the ECFS-Clinical Trial Network, Cystic Fibrosis Europe, other national cystic fibrosis patient associations and the European Cystic Fibrosis Society with its several working groups. There are also close contacts to the US patient organization Cystic Fibrosis Foundation which is maintaining the CFF-TDN also conducting clinical trials in the field of cystic fibrosis.

MI is coordinator and contact point of the CF-CTN. We may provide you with a price list of our services and an individual offer for your special request.

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