

German CF-Registry

Annual Report 2015

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Impressum

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Preface



**Dr. med.
Lutz Nährlich**

Medical Director
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Since the publication of the last report, three years have gone by. We have made use of this time to transform the basic structure of the Cystic Fibrosis Registry (CF-Registry), unchanged since 1995. We have restructured the data fields, developed a new piece of Registry software (Muko.web) for a web-based data base, implemented a centralised pseudonymisation (so-called Mainzel list [Mainzelliste]), and installed a new data-protection concept. In collaboration with the local CF Team, from Summer 2015 we have been tackling administrative hurdles on-site; we have transferred the locally stored data from Muko.dok into the new database; we have collected patient consent according to new data protection concept; we have carried out our first quality controls; and we have stepped up data recording. The collective report at hand is based on the tier 1 data fields compiled from Muko.dok and/or Muko.web; from the 2016 reporting year, the expanded data fields are to be recorded for all CF sites. From this analysis, we hope to achieve a detailed overview of the health status and care of patients.

In the collective report at hand, the data from 5331 patients (2014:5187) from 90 CF sites (2012: 80) are presented in a new, focussed report format based on the essential facts. The proportion of adult patients amounts to 56.5% and the median age is of 20 years.

The CFTR-genotyping, important for mutation-specific treatments, is known in 98.8% of all patients. For 91%, both mutations are evident. A normal nutritional status can be seen in 70% of children and young patients, and in 76.8% of adults. In the 16-17 age range, 58% of the young people had an FEV1%pred of $\geq 80\%$. *Pseudomonas aeruginosa* has been detected in 14.3% of children and young patients, and in 40.2% of adults, at least once per year.

All of this would not have been possible without the trust placed in us by you all, and the extraordinary accomplishments, over and above the routine work of all those involved. For this, I would like to wholeheartedly thank all the CF sites teams and patients. My thanks also go out to the CF-Registry working group, the company Axaris (Mrs. Jaumann, Mr. Müller, Mr. Volk) and to the data management team of MH Hannover (Mrs. Dipl. Math. Wiese, Mrs. Usascheva, Mrs. Mamone, Mrs. Oey). My special thanks go out also to Mr. Burkhart from the Mukoviszidose Institut for his tireless commitment to project management. Keep up to date with the Register.

Gießen, November 2016

Dr. med. Lutz Nährlich

Description of the Collective & Methodology for Data Analysis

For the **2015 reporting year, history data sets from 5331 patients** have been entered for analysis. For these patients, there is at least one data set with size, FEV1 or evidence of bacteria, and the patient had consented, or was deceased, before a new patient consent could be obtained. For the evaluations of lung function, patients were excluded who had undergone a lung transplant in 2015, or had previously had a lung transplant, and those who were under the age of 6 and had no measurements for lung function, such that 5132 data sets were available. In total, 127 values (2.4%) are missing for the evaluation of nutritional status. For 502 patients, information is missing regarding complications.

The history data sets are recorded into the so-called tier 1 hospital departments on a once-yearly basis as the status for the entire calendar year, and the visit-related data sets for the so-called tier 2 hospital departments is aggregated if appropriate. For patients of ≥ 6 years with lung function measurements, the time of the examination with the best FEV1%pred and the associated body measurements will be chosen as the examination date from 2015. Where FEV1-values are missing and for children <6 years, the last available body measurements from the reporting year are used. A complication presenting at least once per year or microbiological evidence determines the severity level for the whole reporting year. Where there are history data sets available from several hospital departments, these shall be aggregated to a data set for the collective report according to the above-mentioned rules.

All patients having died during any respective reporting year that have died are entered into the mortality analysis, regardless of whether a history data set is available or not. Those patients having revoked their consent before their death will, nevertheless, be excluded. Patient age was calculated at the end of the respective reporting year in full years for all patients not recorded as deceased. For deceased patients who died after the end of the reporting year, the age whilst still alive is recorded. In the case of patients that died during the reporting year, the age at time of death is used, in full years. For deceased patients with no recorded date of death, the age in full years at the end of the reporting year was calculated.

Lung function was calculated using the reference values according to Wang et al (Pediatr Pulmonol 1993; 15: 793) for young male patients between 6-18 years, and young female patient between 6-15 years, and according to Hankinson et al (Am Respir Crit Care Med 1999; 159:179) for adult males' ≥ 18 years and women ≥ 16 years. For BMI calculations, the reference study according to the KiGGS study (Robert-Koch Institute: Reference percentiles for anthropometric measured values and blood pressure from the study on the health of children and young people [Studie zur Gesundheit von Kindern und Jugendlichen] (KiGGS); Berlin: RKI-Hausdruckerei; 2013) and for children under 4 months of age, the reference values according to Kromeyer-Hauschild (Monatsschr Kinderheilkd 2001; 149: 807) are used.

Brief overview CF Germany

	2013	2014	2015
Data version	28.10.2016	28.10.2016	28.10.2016
Participating institutions	90	90	90
Participating patients	5101	5187	5331
Age in years; Median	19	19	20
Proportion of adults (≥ 18 years); %	55.1%	55.4%	56.5%
Male patients in %	51.5%	51.8%	51.8%
Newly diagnosed	119	135	140
Age when newly diagnosed in years; median	1.75	0.59	0.62
<i>of which were diagnosed during newborn screening</i>	16.1%	24.4%	22.4%
Deaths; Number and % of all patients	69 (1.4)	72 (1.4)	80 (1.5)
Age at death in years; Median (25.-75.P)	33 (25-40)	33 (25-40)	32 (24-38)
Transplants:	39	27	28
<i>of which lung transplants</i>	31	23	23
<i>of which liver transplants</i>	6	3	2
<i>of which liver and lung transplants</i>	0	1	2
<i>of which liver and pancreas transplants</i>	1	0	1
<i>of which other organs</i>	1	0	0

Table 1: Brief overview CF Germany 2015

Age structure

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

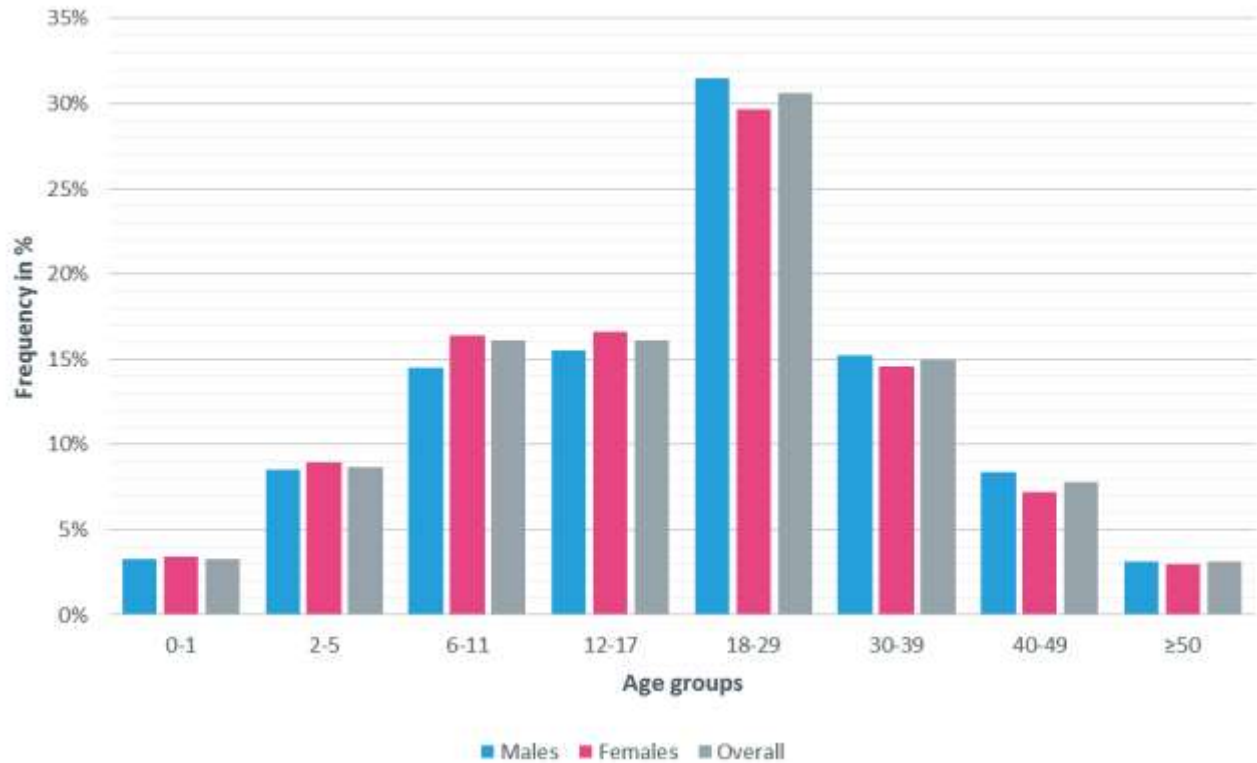


Figure 1: Age distribution, 2015

	Male	Female	Total
Amount	2763	2567	5330
Mean value; Years	22	21	21
Median value; Years	20	19	20
Minimum value; Years	0	0	0
Maximum value; Years	77	73	77
Percentile 25; Years	11	10	11
Percentile 75; Years	30	29	30
Amount < 18 years	1157	1164	2321
Amount ≥ 18 years	1606	1403	3009

Table 2: Age distribution, 2015

CF-Diagnosis

4a. Newly diagnosed in 2015

In 2015, 140 patients were newly diagnosed. From these, 22.4% were diagnosed through newborn screening, and 15.2% through meconium ileus. The age distribution of the newborn patients is represented in the following table:

Mean value	Median value	Minimum	Maximum	Percentile 25	Percentile 75
4.92	0.62	0.00	51.92	0.16	4.13

Table 3: Age at diagnosis for newly diagnosed patients, 2015; key-figures

4b. Age at diagnosis

Age at diagnosis	Frequency	Percentage	Cumulative percentage
0-3 months	53	37.9	37.9
4-6 months	17	12.1	50.0
7-11 months	7	5.0	55.0
1 year	11	7.9	62.9
2 years	11	7.9	70.7
3 years	< 5	2.9	73.6
4 years	6	4.3	77.9
5 years	< 5	2.1	80.0
6-11 years	11	7.9	87.9
12-17 years	< 5	3.6	91.4
≥ 18 years	12	8.6	100.0

Table 4: Age at diagnosis for newly diagnosed patients, 2015

CF-Diagnosis

4c. Genotyping

For 5269 (98.8%) of all patients, a genotyping was available. For the remaining cases, 15 patients (0.3%) had no genotyping carried out on them up to that point, and the remaining 47 (0.9%) have been entered as unknown for this field.

	Frequency	Percentage
F508del homozygote	2475	47.0
F508del heterozygote: Two mutations identified	1788	33.9
F508del heterozygote: Two mutations not identified	259	4.9
No evidence of F508del: Both mutations identified	531	10.1
No evidence of F508del: Only one mutation identified	68	1.3
No evidence of F508del: No mutations identified	148	2.8
Total	5269	100.0

Table 5: Mutations combinations, 2015

The following shows the frequencies for the individual alleles, where only those with an absolute frequency of at least 50 are shown individually.

	Frequency	Percentage
F508del(p.Phe508del,c.1521_1523delCTT)	6997	66.4
G542X(p.Gly542X,c.1624G>T)	204	1.9
N1303K (p.Asn1303Lys ,c.3909C>G)	199	1.9
R553X(p.Arg553X,c.1657C>T)	197	1.9
G551D(p.Gly551Asp,c.1652G>A)	180	1.7
CFTRdele2,3(p.Ser18ArgfsX16,c.54-5940_273+10250del21kb)	139	1.3
R347P(p.Arg347Pro,c.1040G>C)	137	1.3
3849+10kbC->T(No protein name,c.3717+12191C>T)	103	1.0
1717-1G->A (No protein name,c.1585-1G>A)	84	0.8
W1282X (p.Trp1282X ,c.3846G>A)	73	0.7
2789+5G->A (No protein name,c.2657+5G>A)	71	0.7
2183AA->G(p.Lys684SerfsX38 ,c.2051_2052delAAinsG)	65	0.6
Other mutation	1466	13.8
Mutation not identified	593	5.6
Unknown	30	0.3
Total	10538	100.0

Table 6: CFTR Genotyping, 2015

Nutritional status

5a. Nutritional status for children and young patients under 18 years of age

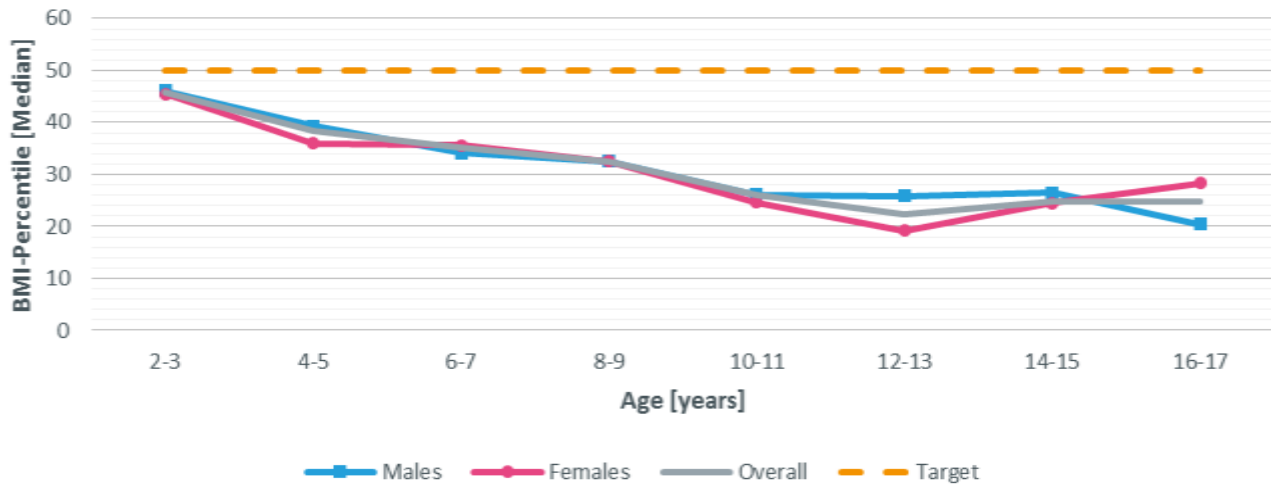


Figure 2: Nutritional status for children and adolescents under 18 years, 2015

	All			Male			Female		
Age	N	Median value	IQR	N	Median value	IQR	N	Median value	IQR
< 2	177	24.4	6.7-54.7	91	25.7	5.7-55.5	86	22.8	6.9-54.7
2-3	204	45.8	20.1-55.5	104	46.0	23.1-67.1	100	45.4	18.1-65.4
4-5	240	38.4	12.9-62.8	119	39.3	16.7-62.3	121	36.0	12.6-64.1
6-7	289	35.3	18.1-54.7	141	34.1	16.4-54.7	148	35.6	19.0-54.6
8-9	294	32.5	14.0-55.8	135	32.6	15.5-59.7	159	32.5	13.0-51.8
10-11	269	26.0	11.8-48.9	142	26.1	11.3-44.9	127	24.6	11.9-51.4
12-13	266	22.3	8.5-73.7	134	25.9	9.7-43.7	132	19.2	7.9-43.3
14-15	310	24.8	8.6-45.6	145	26.5	7.3-45.8	165	24.5	9.2-44.1
16-17	321	24.8	8.4-50.8	159	20.5	5.7-41.9	162	28.4	11.8-53.0
Total	2370	29.3	11.8-53.2	1170	29.1	11.9-53.2	1200	29.7	11.7-53.2

Table 7: BMI percentiles for children and adolescents under 18 years of age, 2015 (Reference: KIGSS Study; and 0-3 months of life Kromeyer-Hauschild)

	Male	Female	Total
< 15. Percentile (%)	358 (30.6%)	353 (29.4%)	711 (30.0%)
≥ 50. Percentile (%)	323 (27.6%)	341 (28.4%)	664 (28.0%)

Table 8: Nutritional status for children and adolescents under 18 years of age: BMI Percentile <15 & ≥50; 2015

Nutritional status

5b. Nutritional status for adults, over 18 years of age



Figure 3: Nutritional status for adults, over 18 years of age, 2015

	All			Male			Female		
Age	N	Median value	IQR	N	Median value	IQR	N	Median value	IQR
18-19	284	20.3	18.4-22.2	166	20.2	18.4-22.3	118	20.3	18.3-21.8
20-24	636	20.6	18.7-22.4	319	20.6	18.6-22.8	317	20.4	18.8-22.2
25-29	613	21.2	19.2-23.1	332	21.9	20.0-23.8	281	20.1	18.8-22.1
30-34	460	20.9	19.0-23.2	254	21.7	19.6-24.1	206	20.1	18.5-22.3
35-39	300	21.3	19.3-23.2	156	21.9	20.2-24.1	144	20.5	18.6-22.3
40-44	209	21.8	19.8-23.6	115	22.2	19.8-23.9	94	21.2	19.7-23.2
45-49	184	22.0	20.1-24.2	104	22.7	20.8-24.7	80	20.9	19.5-23.1
≥ 50	145	22.2	20.2-24.4	77	22.5	20.7-24.4	68	21.4	19.8-24.5
Total	2831	21.0	19.1-23.1	1523	21.6	19.5-23.7	1308	20.4	18.8-22.3

Table 9: BMI for adults, over 18 years of age, 2015

	Male	Female	Total
< 19 kg/m ² (%)	299 (19.6%)	357 (29.1%)	656 (23.2%)

Table 10: Nutritional status for adults: BMI < 19 kg/m², 2015

Lung function

(not including lung transplant patients)

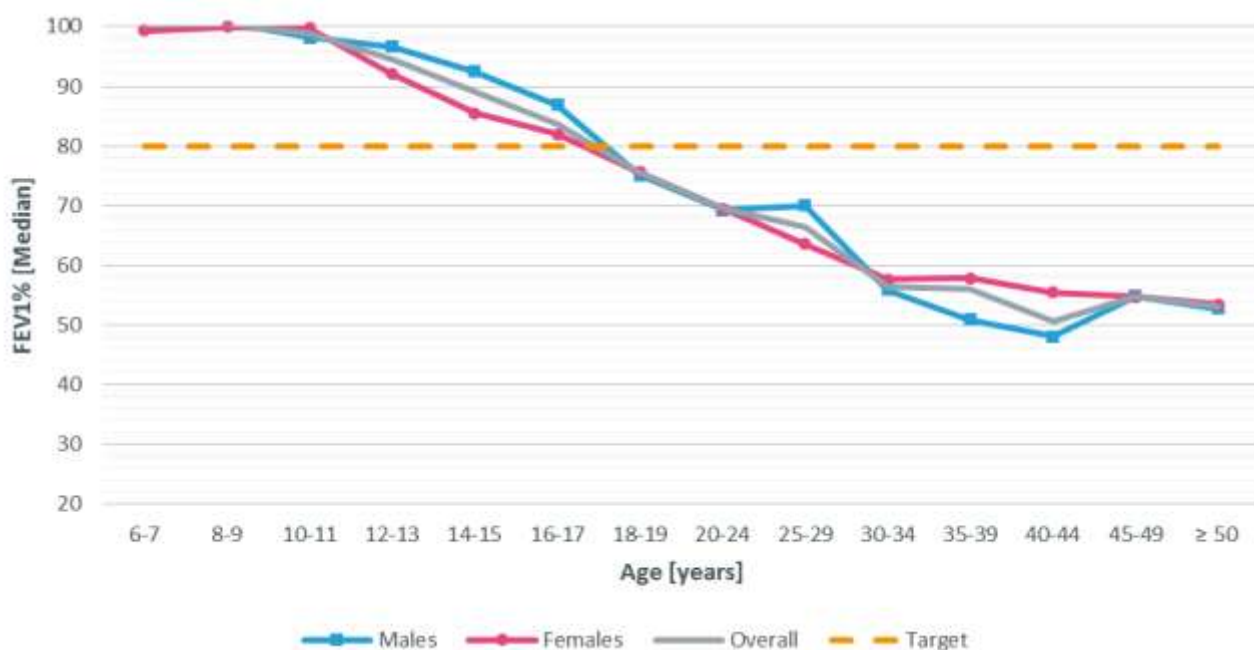


Figure 4: FEV1% value according to Wang and Hankinson, 2015

	All			Male			Female		
Age	N	Median value	IQR	N	Median value	IQR	N	Median value	IQR
6-7	278	100.4	90.8-110.7	135	100.6	92.3-111.6	143	99.3	89.4-110.7
8-9	287	100.4	88.0-108.8	135	100.8	88.2-110.1	152	100.0	87.4-106.1
10-11	270	98.8	90.4-106.9	137	98.1	89.7-106.3	133	99.8	90.6-107.2
12-13	257	94.5	81.9-105.8	131	96.6	85.3-107.1	126	92.0	79.7-104.1
14-15	311	89.0	75.1-102.3	147	92.4	79.6-103.9	164	85.5	69.5-100.8
16-17	312	83.6	68.8-97.7	154	86.9	71.7-101.3	158	82.0	68.1-95.4
18-19	275	75.5	54.9-92.2	160	75.0	55.5-94.2	115	75.6	52.6-89.0
20-24	609	69.5	50.1-88.2	309	69.3	50.1-86.9	300	69.5	50.0-89.9
25-29	570	66.4	47.3-82.9	312	70.0	50.8-83.2	258	63.5	44.5-82.9
30-34	405	56.5	39.2-77.6	227	55.8	39.5-78.4	178	57.7	38.9-76.2
35-39	272	56.0	38.7-73.8	145	50.9	34.9-76.5	127	57.8	42.1-70.5
40-44	188	50.6	36.7-72.1	106	48.1	34.9-71.5	82	55.5	38.2-73.3
45-49	159	54.8	35.8-70.5	88	54.8	34.9-75.5	71	54.7	36.2-65.9
≥ 50	127	53.2	36.8-75.2	69	52.7	34.9-75.2	58	53.5	41.7-74.1

Lung function

(not including lung transplant patients)

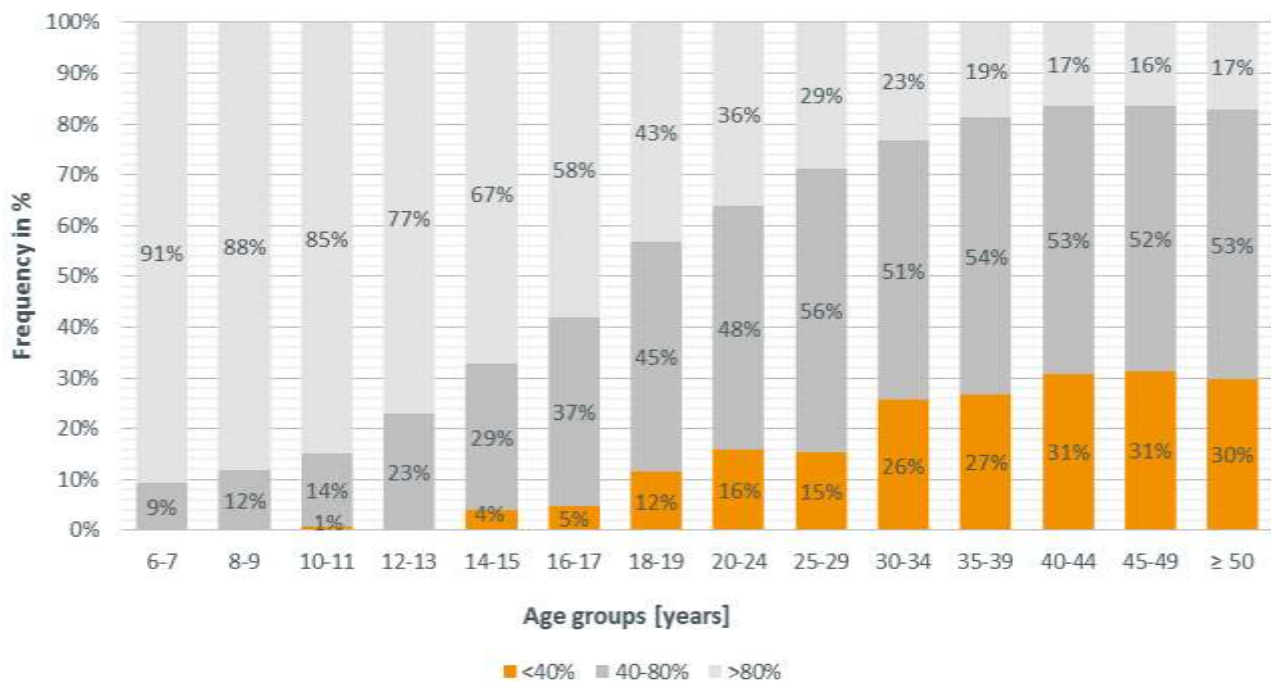


Figure 5: Age-related frequencies of severities of FEV1% values (Categories >80%, 40-80% & <40%), 2015

Lung infections

Lung infections (not including lung transplant patients; evidence of at-least yearly occurrence)

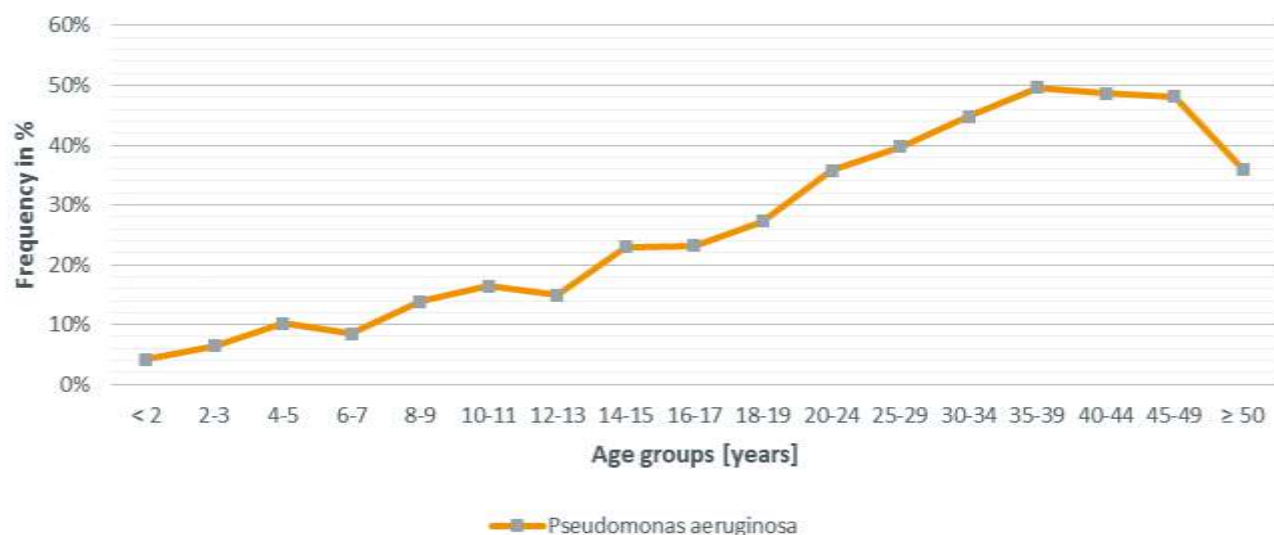


Figure 6: Age-related frequency of Pseudomonas aeruginosa, 2015

Patient age	Pseudomonas aeruginosa (N)	Pseudomonas aeruginosa %	Burkholderia cepacia (N)	Burkholderia cepacia (%)	Total
< 2	7	4.2%	0	0.0%	168
2-3	13	6.4%	0	0.0%	202
4-5	26	10.2%	0	0.0%	255
6-7	20	8.5%	<5	0.4%	236
8-9	38	13.8%	<5	1.1%	275
10-11	45	16.4%	<5	1.1%	274
12-13	38	14.9%	<5	1.6%	255
14-15	64	23.0%	5	1.8%	278
16-17	69	23.2%	<5	1.3%	297
18-19	85	27.3%	11	3.5%	311
20-24	217	35.8%	16	2.6%	606
25-29	231	39.7%	15	2.6%	582
30-34	180	44.8%	7	1.7%	402
35-39	141	49.6%	6	2.1%	284
40-44	97	48.7%	<5	1.5%	199
45-49	76	48.1%	<5	1.9%	158
≥ 50	50	36.0%	<5	1.4%	139
Total	1397	28.4%	83	1.7%	4921
< 18 years	320	14.0%	20	0.9%	2240
≥ 18 years	1077	40.0%	63	2.3%	2681

Table 12: Frequency in % and number of patients with evidence of Pseudomonas aeruginosa & Burkholderia cepacia complex, 2015

Lung infections

Lung infections (not including lung transplant patients; evidence of at-least yearly occurrence)

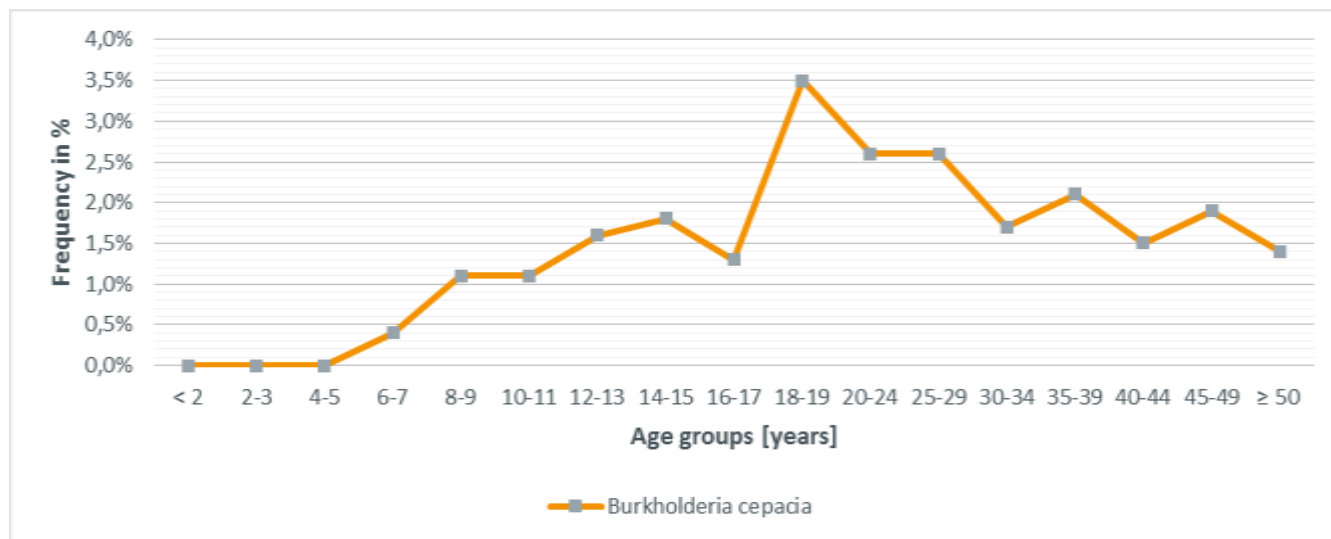


Figure 7: Age-related frequency of Burkholderia cepacia, 2015

Complications

	< 18 years (n=2112)	≥ 18 years (n=2716)	Total (n= 4828)
ABPA	4.7%	10.8%	8.1%
Haemoptysis	0.9%	9.3%	5.6%
Pneumothorax	0.3%	1.9%	1.2%
Exocrine pancreatic insufficiency	87.2%	87.1%	87.1%
Diabetes mellitus	4.3%	32.4%	20.1%
DIOS	4.5%	6.7%	5.7%
Liver disease	26.6%	36.3%	32.0%

Table 13: Frequency of complications <18, or >18 years, 2015

Mortality

In the 2015 reporting year, 80 patients died (50 female and 30 male). The main causes of death were cardio-pulmonary (77.0%), hepato-intestinal (1.4%), transplant-related (1.4%), and malignant diseases (1.4%). In the remaining 9.5% of cases, the cause of death was through 'other', or 'unknown' causes. The age at death was distributed as follows:

	Amount	Mean value	Median value	Minimum	Maximum	Percentile 25	Percentile 75
Age at death; in full years	80	32	32	8	75	24	38

Table 14: Age at death, 2015

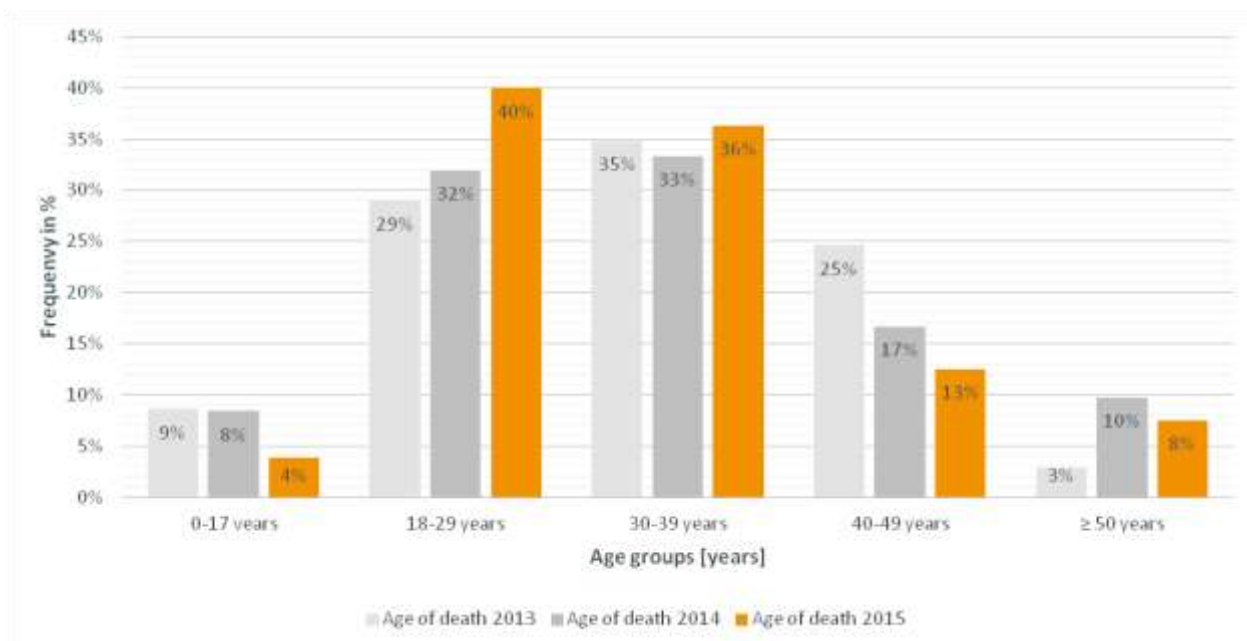


Figure 8: Frequency deceased Patient by age groups, 2013-2015

	Amount	Percentage
0-17 years	<5	3.8%
18-29 years	32	40.0%
30-39 years	29	36.3%
≥ 40 years	10	12.5%
≥ 50 years	6	7.5%

Table 15: Number and frequency for age groups, age at death, 2015

Care structure

In the 2015 reporting year, 90 CF sites were involved in the CF-Registry. 54 CF sites treated less than 50 patients, and 36 CF sites treated more than 50 patients.

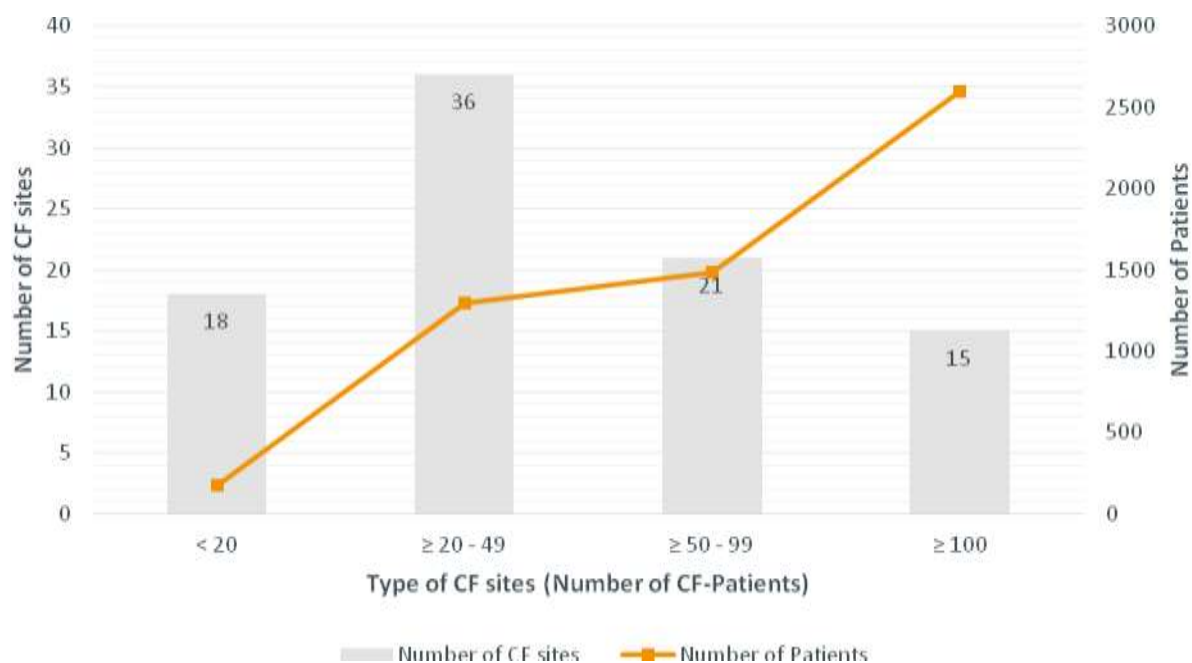


Figure 8: Number of CF-Patients in the documenting CF sites

Overview of participating CF sites

The following lists the CF sites involved in this reporting year. The CF-Registry would like to whole-heartedly thank the participating CF sites and their team members for their hard work and collaboration.

Location	Hospital	Department
Aachen	Luisenhospital Aachen	Innere Medizin Mukoviszidose-Zentrum für Erwachsene
Aachen	Kinderarztpraxis Laurensberg	Aachener Mukoviszidose Ambulanz für Kinder und Jugendliche
Aalen	Ostalb-Klinikum Aalen	Klinik für Kinder und Jugendmedizin Pneumologie und Allergologie
Aue	Helios Klinikum Aue	Klinik für Kinder- und Jugendmedizin
Augsburg	Josefinum KJF Krankenhaus für Kinder und Jugendliche	CF- Ambulanz
Baden-Baden	Klinikum Mittelbaden Baden-Baden Balg	Mukoviszidose-Ambulanz
Berlin	Helios-Klinikum Berlin Buch	Klinik für Kinder- und Jugendmedizin
Berlin	Charité – Universitätsmedizin Berlin	Klinik für Pädiatrie Christiane Herzog-Zentrum Berlin Mukoviszidose-Ambulanz
Berlin	Sana Klinikum Lichtenberg	Klinik für Kinder- und Jugendmedizin Mukoviszidosezentrum
Bielefeld	Evangelisches Krankenhaus Bielefeld	Lehrkrankenhaus der Universität Münster Klinik für Kinder und Jugendmedizin Kinderpneumologie
Bochum	St. Joseph-Hospital der Ruhr-Universität Bochum	Klinik für Kinder- u. Jugendmedizin
Bonn	Universitätsklinikum Bonn	Zentrum für Kinderheilkunde Allgemeine Pädiatrie Allergologie und Pulmologie
Brandenburg	Städtisches Klinikum Brandenburg	Kinder- und Jugendmedizin Mukoviszidose-Ambulanz
Bremen	Gesundheit Nord gGmbH Klinikverbund Bremen	Klinikum Links der Weser Christiane-Herzog-Ambulanz für Mukoviszidose
Chemnitz	Poliklinik Chemnitz	Praxis für Kinder- und Jugendmedizin MVZ Am Rathaus
Cottbus	Carl-Thiem-Klinikum Cottbus	Akademisches Lehrkrankenhaus der Charité Klinik für Kinder und Jugendmedizin
Dresden	Universitätsklinikum Carl Gustav Carus	Klinik und Poliklinik für Kinder- und Jugendmedizin Mukoviszidose-Centrum "Christiane Herzog"
Ort	Ambulanz	Abteilung
Düsseldorf	Universitätsklinikum Düsseldorf	Zentrum für Kinder- und Jugendmedizin Klinik für Allgemeine Pädiatrie, Neonatologie und

		Kinderkardiologie Ambulanz für Kinderpneumologie und Allergologie
Erfurt	Helios Klinikum Erfurt GmbH	Klinik für Kinder und Jugendmedizin Mukoviszidose-Ambulanz
Erlangen	Universitätsklinikum Erlangen	Kinder- und Jugendklinik Mukoviszidose-Ambulanz für Kinder und Jugendliche
Erlangen	Universitätsklinikum Erlangen	Medizinische Klinik 1 Gastroenterologie, Pneumologie und Endokrinologie
Essen	Ruhrlandklinik Westdeutsches Lungenzentrum am Universitätsklinikum Essen	Abteilung Pneumologie
Essen	Universitätsklinikum Essen	Klinik für Kinderheilkunde III Abteilung für Pädiatrische Pneumologie und Schlafmedizin Mukoviszidose Zentrum
Esslingen	Klinikum Esslingen	Klinik für Kinder und Jugendliche Mukoviszidose-Ambulanz
Frankfurt	Klinikum der Johann Wolfgang- Goethe-Universität	Christiane Herzog CF-Zentrum für Kinder, Jugendliche und Erwachsene
Frankfurt	St. Elisabethen Hospital	Katharina Kasper-Kliniken Akademisches Lehrkrankenhaus Innere Medizin-Pneumologie
Frankfurt/Oder	Klinikum Frankfurt (Oder)	Kinderzentrum
Freiburg	Universitätsklinikum Freiburg	Klinik für Pneumologie CF-Erwachsenenambulanz
Freiburg	Universitätsklinikum Freiburg	Zentrum für Kinder- und Jugendmedizin Allergologie, Pneumologie und Mukoviszidose
Gerlingen	Robert-Bosch-Krankenhaus Klinik Schillerhöhe	Pneumologie und Pneumologische Onkologie Mukoviszidose-Ambulanz
Gießen	Universitätsklinikum Gießen und Marburg GmbH	Zentrum für Innere Medizin Pneumologie und Intensivmedizin Mukoviszidose-Ambulanz für Erwachsene
Gießen	Universitätsklinikum Gießen und Marburg GmbH	Zentrum für Kinderheilkunde und Jugendmedizin Abteilung Allgemeine Pädiatrie und Neonatologie
Ort	Ambulanz	Abteilung
Greifswald	Universitätsmedizin Greifswald	Klinik und Poliklinik für Kinder und Jugendmedizin Abteilung Allgemeine Pädiatrie/ Pädiatrische Pulmologie
Greiz	Kreiskrankenhaus Greiz GmbH	Akademisches Lehrkrankenhaus des Universitätsklinikums Jena CF-Ambulanz der Kinderklinik
Halle	Klinikum der Martin-Luther- Universität Halle-Wittenberg	Klinik für Kinder- und Jugendmedizin und Klinik für Innere Medizin
Hamburg	Kinderärztliche Gemeinschaftspraxis Dr. C. Runge, Dr. W. Sextro, Dr. I. Held	CF Zentrum Altona/Hamburg
Hamm	Evangelisches Krankenhaus Hamm gGmbH	Klinik für Kinder- und Jugendmedizin
Hannover	Medizinische Hochschule Hannover	Abteilung Pneumologie CF-Ambulanz für Erwachsene
Hannover	Medizinische Hochschule Hannover	Zentrum für Kinderheilkunde und Jugendmedizin Mukoviszidose (Cystische Fibrose) Ambulanz

Heidelberg	Thoraxklinik am Universitätsklinikum Heidelberg	Mukoviszidose Zentrum Heidelberg
Heidelberg	Universitätsklinikum Heidelberg	Zentrum für Kinder- und Jugendmedizin Angelika-Lautenschläger-Klinik Kinderheilkunde III Mukoviszidosezentrum Heidelberg
Heilbronn	SLK-Kliniken Heilbronn GmbH	Klinik für Kinder- und Jugendmedizin/ Perinatalzentrum
Homburg	Universitätsklinikum des Saarlandes Homburg	Klinik für Allgemeine Pädiatrie und Neonatologie
Homburg	Universitätsklinikum des Saarlandes Homburg	Klinik für Innere Medizin V Pneumologie, Allergologie, Beatmungs- und Umweltmedizin Mukoviszidose-Ambulanz für Erwachsene
Jena	Universitätsklinikum Jena	Klinik für Kinder- und Jugendmedizin, Sektion Pädiatrische Pneumologie und Mukoviszidose
Karlsruhe	Städtisches Klinikum Karlsruhe GmbH	Klinik für Kinder- und Jugendmedizin Pneumologie Mukoviszidose-Ambulanz
Kassel	Klinikum Kassel	Kinderkrankenhaus Park Schönfeld Klinik für Kinder und Jugendmedizin Kinderpneumologie
Ort	Ambulanz	Abteilung
Kiel	Universitätsklinikum Schleswig-Holstein Campus Kiel	Mukoviszidose Zentrum für Erwachsene
Kiel	Städtisches Krankenhaus Kiel GmbH	Kinder und Jugendmedizin Mukoviszidose Zentrum Kiel
Koblenz	Gemeinschaftsklinikum Mittelrhein gGmbH	Klinik für Kinder und Jugendmedizin Koblenz Institutsambulanz Mukoviszidose
Köln	Uniklinik Köln	Klinik und Poliklinik für Kinder- und Jugendmedizin Pädiatrische Pneumologie und Allergologie Mukoviszidose-Zentrum
Köln	Kliniken Köln	Lungenklinik Köln-Merheim Mukoviszidose-Ambulanz
Krefeld	Helios Klinikum Krefeld	Kinder- und Jugendmedizin, Mukoviszidose-Ambulanz für Kinder, Jugendliche und Erwachsene
Leipzig	Universitätsklinik und Poliklinik	für Kinder- und Jugendmedizin der Universität Leipzig
Leipzig	Universitätsklinikum Leipzig	Medizinische Klinik und Poliklinik I Abteilung für Pneumologie Mukoviszidose Ambulanz
Lübeck	Universitätsklinikum Schleswig-Holstein Campus Lübeck	Klinik für Kinder- und Jugendmedizin Spezialambulanz für Cystische Fibrose (Mukoviszidose)
Magdeburg	Otto v. Guericke Universität	Zentrum für Kinderheilkunde
Magdeburg	Otto v. Guericke-Universität	Klinik für Pneumologie
Mainz	Universitätsmedizin Mainz	Zentrum für Kinder- und Jugendmedizin Pädiatrische Pneumologie, Allergologie und Mukoviszidose
Mannheim	Universitätsmedizin Mannheim	Klinik für Kinder- und Jugendmedizin Pulmologie, Infektiologie, Allergologie

Marburg	Universitätsklinikum Marburg	Klinik für Kinder- und Jugendmedizin Mukoviszidose-Ambulanz
München	LMU Klinikum der Universität München Campus Innenstadt	Medizinische Klinik Pneumologie, Mukoviszidose Zentrum
München	Kinderklinik München Schwabing	CF-Ambulanz
München	Klinikum der Universität München	Dr. von Haunersches Kinderspital Christiane-Herzog-Ambulanz
Ort	Ambulanz	Abteilung
München - Pasing	Lungenärztliche Praxis	Prof. Dr. med. Fischer und Dr. med. Michael Baborka
Münster	Universitätsklinikum Münster	Klinik für Kinder- und Jugendmedizin Allgemeine Pädiatrie Mukoviszidosezentrum Albert-Schweitzer-Campus 1, Gebäude A1
Münster	Clemenshospital Münster GmbH	Pädiatrische Pneumologie und Allergologie Mukoviszidose-Ambulanz
Neubrandenburg	Dietrich Bonhoeffer Klinikum Neubrandenburg	Kinder- und Jugendmedizin Pneumologie und Allergologie Zentrum Mukoviszidose
Oldenburg	Klinikum Oldenburg	Elisabeth-Kinderkrankenhaus Klinik für Pädiatrische Pneumologie und Allergologie, Neonatologie, Intensivmedizin und Kinderkardiologie Mukoviszidose-Ambulanz
Osnabrück	Christliches Kinderhospital Osnabrück	Zentrum für Kinder- und Jugendmedizin, Mukoviszidose Ambulanz
Passau	Kinderklinik Dritter Orden Passau	Akademisches Lehrkrankenhaus der TU München Sozialpädiatrisches Zentrum für chronisch erkrankte Kinder und Jugendliche
Potsdam	Klinikum Westbrandenburg	Klinik für Kinder und Jugendmedizin, Mukoviszidose Ambulanz
Ravensburg	Oberschwabenklinik gGmbH Ravensburg	Kinder- und Jugendmedizin
Regensburg	Krankenhaus Barmherzige Brüder Regensburg Klinik St. Hedwig	Kinder- und Jugendmedizin Mukoviszidose-Ambulanz
Rostock	Universität Rostock	Klinik für Kinder- und Jugendmedizin Mukoviszidose-Zentrum
Schwerin	Helios Kliniken Schwerin	Klinik für Kinde- und Jugendmedizin Mukoviszidose Ambulanz
Solingen	Städtisches Klinikum Solingen	Klinik für Kinder- und Jugendmedizin
Stuttgart	Klinikum Stuttgart - Olgahospital	Ambulanz für Mukoviszidose und seltene Erkrankungen
Trier	Klinikum Mutterhaus der Borromäerinnen gGmbH	Innere Medizin I Mukoviszidose Ambulanz für Erwachsene
Trier	Klinikum Mutterhaus der Borromäerinnen gGmbH	Kinder und Jugendmedizin Kinderpneumologie Mukoviszidose Ambulanz für Kinder
Ort	Ambulanz	Abteilung

Tübingen	Universitätsklinik für Kinder- und Jugendmedizin Tübingen	Abt. 1, Mukoviszidose-Ambulanz
Ulm	Universitätskinderklinik Ulm	Kinder- und Jugendmedizin Mukoviszidose-Ambulanz
Vechta	St.-Marienhospital Vechta	Klinik für Kinder- und Jugendmedizin, Fachbereich Allergologie und Pulmologie
Wangen	Fachkliniken Wangen GmbH	Klinik für Pneumologie
Wangen	Fachkliniken Wangen GmbH	Kinderklinik für Atemwegserkrankungen und Allergien
Wesel	Marienhospital Wesel	Akademisches Lehrkrankenhaus der Westfälischen Wilhelms-Universität Münster Klinik für Kinder und Jugendmedizin Allergologie, Pneumologie mit Mukoviszidoseambulanz
Wiesbaden	Stiftung Deutsche Klinik für Diagnostik GmbH	Kinder- und Jugendmedizin Mukoviszidose-Ambulanz
Worms	Klinikum Worms	Kinderklinik Mukoviszidose-Ambulanz
Würzburg	Universitätsklinikum Würzburg	Christiane Herzog Ambulanz für Mukoviszidose
Zwickau	Heinrich-Braun-Klinikum Zwickau	Klinik für Kinder- und Jugendmedizin Mukoviszidose-Ambulanz