

Information on hygienic behaviour at events of the German CF Association Mukoviszidose e.V.

1. Background

Contracting CF-relevant pathogens is a possible risk when people with cystic fibrosis (pwCF) come together. Internationally, this circumstance is handled very differently. In some countries, CF organisations refrain entirely from meetings between pwCF; in some cases, only one pwCF is allowed in a room. We, the German CF Association *Mukoviszidose e.V.*, agree that the benefit that affected people (pwCF and parents) gain from exchange with others at meetings is very fruitful and essential. Therefore, it must be weighed against the risk of cross-infection.

The Board of the *Mukoviszidose e.V.* enacted the following guidelines for hygienic behaviour in 2017 after intensive consultation with their internal committees to enable more people to participate in the association's events. So that they can meet, share experiences, and learn from each other. At the same time, the board appeals to all participants to take personal responsibility and to adhere to certain hygienic behaviours. The board's decision was based on the results of a research project carried out by an interdisciplinary working group formed by the internal *Board for Promoting Therapy and Quality (TFQ)*. They systematically searched the scientific literature, extracted the data in collaboration with a scientific institute, and conducted an exploratory expert survey.

The systematic literature search yielded approximately 300 publications, of which 58 were considered relevant and analysed in detail. Twenty-two statements on the following ten topics were derived from evidence tables: 1) target groups, 2) exclusion criteria, 3) disinfection, 4) coughing, 5) face masks, 6) accommodation, 7) sanitary facilities, 8) sputum management, 9) shared meals and 10) ventilation. Direct evidence from the literature was available for six statements. An exploratory expert survey with twenty-six CF doctors of outpatient clinics, microbiologists, and hygienists assessed the remaining sixteen statements. This combined approach confirmed or refuted twenty statements. There was no clear evidence for two statements. However, the additional information generated through the exploratory approach allowed for the pragmatic handling of these unclear issues. The results formed the basis for the guidelines. Details on the methodology and results are described in the project report (see link below).

It is out of the question that guidelines and recommendations will ultimately prevent the risk of germ transmission. However, specific actions can at least significantly reduce the likelihood of transmission. The evidence-based guidelines of the German CF Association *Mukoviszidose e.V.* include recommendations for:

- 1) Event planning (such as exclusion of risk persons, participant training and empowerment, and appropriate infrastructure like disinfectants, room equipment etc.)

- 2) Participants' behaviour (such as regular hand hygiene, compliance with cough, toilet and sputum etiquette, and recommendation to wear face masks)

The work resulted in the following hygiene guidelines. The guidelines and the full report of the working group, including the literature review, can be found in the (German-language) documents at www.muko.info/hygienerichtlinie

Since the new guidelines, the *Mukoviszidose e.V.* also allows pwCF with *Pseudomonas aeruginosa* to participate in seminars and conferences offered by the association, even if the *Pseudomonas* is multi-resistant (class 3MRGN or 4MRGN). PwCF with acute infections or *Burkholderia cepacia*, *Mycobacterium abscessus* or MRSA are not allowed to participate in the association's events. However, the association will enable these pwCF to participate virtually if the format allows it.

2. Guidelines for hygienic behaviour at events of the German Cystic Fibrosis Association *Mukoviszidose e.V.*

Why does this guideline exist?

Events organised by *Mukoviszidose e.V.* require safe conditions for pwCF who attend. Implementing these hygiene guidelines should keep the risk of cross-infection as low as possible. Nevertheless, it is important to emphasise that these guidelines cannot offer 100% safety.

Each participant must take responsibility for deciding whether to participate and considering the residual risk. By registering for an event organised by *Mukoviszidose e.V.*, each participant agrees to adhere to the applicable hygiene guidelines for their protection and the protection of others.

These guidelines apply to all adult participants (with and without CF), speakers, and persons involved in organising the event. Additional regulations may apply to events attended by children with CF. This guideline will be supplemented by additional rules if global infections such as the COVID-19 pandemic require further hygiene measures.

Who is generally not allowed to take part in association events?

1. Persons with evidence of germs that pose a particular risk to people with CF. These are *Burkholderia cepacia*, *Pandora*, *Mycobacterium abscessus* and MRSA.
2. People with acute infections, such as colds, flu, whooping cough, scarlet fever, gastrointestinal infections, etc. Rule of thumb: If you feel ill, don't come!

Which hygiene rules apply for events of Mukoviszidose e.V.?

I protect you - you protect me. Act hygienically together!

DO NOT SHAKE HANDS

We like each other even without a handshake!

DISINFECT YOUR HANDS

Hands should be disinfected regularly, especially after contact with surfaces many people touch, such as tables and door handles. Hand sanitiser is available in automatic dispensers in the event area. In addition, each participant will receive a bottle of disinfectant.

AVOID CONTACT WITH SURFACES

Avoid touching surfaces such as door handles and bannisters wherever possible. If this is not possible, disinfect your hands!

DO NOT SHARE OBJECTS

Movable objects, such as pens, should not be shared (e.g., when signing the list of participants). The organiser will provide sufficient materials. It is recommended that you only use your cutlery when eating. If a buffet is offered, we recommend only touching the serving cutlery with facial tissues (provided) and disinfecting your hands before and after.

KEEP YOUR DISTANCE

Drops containing germs are produced when coughing, speaking loudly, and laughing. However these sink to the ground relatively quickly. Therefore, you should maintain a distance of approximately 1.5 m between people.

COUGH AND SNEEZE CORRECTLY

When coughing and sneezing, you should keep your distance from other people and turn away. Cover your mouth with the crook of your arm. Alternatively, you can also use a handkerchief, which should be disposed immediately. Disinfect your hands afterwards!

OBSERVE SPUTUM ETIQUETTE

Sputum mobilisation should occur in a separate room. The sputum can be disposed of in a regular garbage can with a lid or sealed plastic bag. Disinfect your hands afterwards!

WEAR A FACE MASK

Wearing a face mask reduces the spread of pathogens. Therefore, wearing one during the event is recommended, especially if a distance of 1.5 m cannot be maintained and/or in closed rooms.

Be aware of your responsibility and adhere to these guidelines to protect yourself and others. The organisers may refuse participation to obviously ill persons or persons who do not obey the hygiene rules above.