



CF EUROPE CONFERENCE

Expo Hotel, Avda. Pío XII, 4 · 46009 Valencia

TUESDAY, JUNE 15

“BUILDING STRONG ASSOCIATIONS = BUILDING POSITIVE NETWORKS”

12.00-14.00: CFE Registration

Sandwiches and drink provided

14.00-15.00: Welcome and introduction of participants

Each participant is invited to present themselves and their association in ± 5 minutes.

Short update for those who were present in Paris, more detailed for new participants.

15.00-18.00: CFE conference “Building strong associations = building positive networks”

Each topic will be introduced by CFE and followed by presentations of national associations who have interesting experiences in the field of the presented topic. Focus is on exchange and discussion!

- We invite all of you to prepare a presentation (oral or aided by power point).
- Please present, show, explain, discuss your problems, questions, positive and less positive experiences, possible solutions....

1. Building strong networks within the organization

- Involving patients and families:
 - How to find new members and include CF patients and families
 - How to build a net among the active members
 - How to involve passive members
- Internal organization
 - How to delegate tasks and involve everyone interested
 - Decision making, defining priorities
 - Conflict resolution

2. Building a positive collaboration between CF patients/families and professionals: both experts in their own way

- Relationship and roles of professionals and patients; who does what and takes (final) decisions...
 - within the patient organisation
 - in lobbying/national policy making
 - in education projects (publications, info meetings...)
 - validation of information for patients and families
- How not to offend the doctors because we try do "their job"
- How to create common goals and ways to get there

3. Networking with other disease associations

The European Council Recommendation on European Action in the field of Rare Diseases could have a great impact on the national health policy for European countries, especially the recommendation to establish national plans for rare diseases. Goal is to get ideas on how to influence national health policy by being involved in a broader collaboration

From 19.00: CFE and CFW Welcome reception at the terrace of the hotel



CF EUROPE ANNUAL MEETING
Expo Hotel, Avda. Pío XII, 4 · 46009 Valencia
WEDNESDAY, JUNE 16

09.00-10.00: Aims and projects of CF Europe

- Presentation and discussion on Aims and projects of CF Europe
- Horst Mehl presents a donation to CFE by the German CF Association (Mukoviszidose e.V.)

10.00 - 12.00: CFE General Assembly

1. Approval of the minutes of the GA in Paris, June 8, 2009
2. Approval of the agenda
3. Applications of new members
4. Annual report & finances
5. Preparing the 2011 elections
6. Ongoing and future projects
7. Other business

Help to make this a successful meeting

In order to make this a successful meeting, where people can really learn and exchange, we invite you to prepare this meeting together with your colleagues and the members of your association.

For the sessions on building networks and strong associations

Present your successes and failures; obstacles you met and could overcome...or not or questions you have for your colleague associations.

We ask you to think of 1 or 2 concrete experiences your association had with

1. Involving patients and families;
2. Internal organization
3. Collaboration patients & professionals
4. (Rare) disease collaboration in your country:

Please remember the practical issues mentioned in “Valencia 2010 CFE Programme-info for participants”:

- Let me know as soon as possible who will represent your association in Valencia
- Registration via karleen@muco.be
- All CFE meetings are free
- All CFE meetings take place at the Expo Hotel, Avda. Pío XII, 4 · 46009 Valencia - www.expohotelvalencia.com/en/hotel/ubicacion

Questions? More info?

If you have any questions before the meeting, feel free to contact our secretary or president:

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If you have to reach us while in Valencia, call Karleen on her mobile phone: +32/479 22 37 53