

# Your first international conference for a rare disease Well prepared and successfully performed

This is how we planned and started. Just give it a try!

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# The idea is born – when to start planning??

- **Small meetings with invited participants only can be planned in quite a short time**
- **Members meetings are more tricky**
- **But the most challenging are.....**

# International conferences for patients, clinicians, HCPs and others

**Start planning at least 1.5 years before this event!**

## **Your Team – decide first and try not to change**

- One patient organisation – not the best choice for an international event
- Multiple organisations as partners
  - more ideas for the agenda
  - makes it easier to reach people
  - brings in more well known speakers
  - helps in translation
  - ...

**Even if the organising team consists of 10 or more persons,  
2 of them should be the leads**

## *Who leads the team?*

- Good practice:

2 patient representatives from the country where the meeting will be.

- Why?

They

- know the place and language
- can sign contracts and bank accounts
- know how to find a hotel or location
- know about public transport
- can find translators and childcare
- work closely with the medical team

**Most important:**

**At the end the leads are legally responsible for the whole conference!!**

# Let's get started

## *Discussing the agenda*

- Topics will be easy to find
- Decision: How many days will your conference last?
- Decision: Are there special sections for mainly researchers and only some patient experts planned. This is a nice place to discuss new projects.  
But: You have to make sure who comes in to keep it confidential.
- International clinicians on the plenary agenda will bring international patients as well.
- Include researchers and clinicians you trust in this discussion.  
They can be your „board of experts“ when it comes to problems.
- You might think of a poster session to present new research projects.
- **Don't forget to discuss the agenda with the whole team** in several video meetings .  
Ask them all to read it and give comments.  
This will strengthen your team and lead to broad approval.

**Discuss calmly and don't let antipathies against anyone lead you.**

**Remember: patients, researchers and clinicians will only be successful as a team.**

## *Costs and funding*

- This has to be discussed parallel to the agenda.  
Prepare a business plan even if it has to be changed later.  
You need an overview about the sum you will be able to spend.
- Lots of project funding has to be applied for BEFORE starting the project.
- Ask the patient organisations worldwide for some funding (if it is an international conference).
- Try to get sponsoring from local companies.
- **Do your guests have to pay a fee?**  
Do they have to pay for meals and hotel or is this included?
- It is possible to ask Pharma companies for funding, but don't forget:
  - Some public project funding might be rejected as soon as Pharma becomes a partner.
  - All companies sponsoring your conference want to benefit from it.
  - There might be local regulations about pharma sponsorship in different countries.

**Start early to look for project funding or sponsors.**

**Don't let the conference become dependant on Pharma sponsoring only.**

## What else?

- Simultaneous translation is very helpful.  
The more languages you can offer, the more visitors you will attract.  
You need to engage good translators – these might be expensive!
- Do you need sign language interpreter or text writers?

### In F2F conferences:

- Do you need professional childcare?
- Don't forget to treat your potential visitors with some special events like a sight seeing tour  
or a dinner (you can ask them to pay for it, but it should be organised).

**Do a brainstorming for all the extras you might think of.**

**It is good to have it on a list and delete it later when not needed!**

**Good practise: Split the workload by giving tasks to every player in the team**

**Do this as soon as the task shows up – otherwise this will get lost!**

e.g. Website update and social media, answer questions that come in from (potential) participants, invite speakers and „care for them“, search for translators and give them informations

# Here come your guests



Where do **they** find the conference?

How do **we** find most of our participants worldwide?

- Set up a special website for this event! Update it regularly!!
- Present the agenda nicely laid out and easy to read. Set a link to the registration form. Show it on all websites you can think of .
- Prepare a special logo or picture to be posted with a link to the site (for Facebook, Instagram, Twitter, Whatsapp, Telegram, Signal).

**Don't forget the classical way!**

- Ask all patient organisations to mail to their members. Ask all clinicians to inform their patients and students. Invite all physicians or HCPs and ask your members to do so.
- Ask somebody of your team to send and answer messages in social media on a regular basis (This is polite and is a control for unwanted messages as well).

**Don't wait too long to spread the word!**

**The message should go out 1 year before the conference!**

**Hopefully you can avoid other important events being planned the same days as „your“ chosen date**



# Registration 😊

## Online registration is standard

- Set up a carefully planned form! It is easier to ask all important questions in the first step!! You will never get better answers later on once the registration is confirmed.
- Don't ask questions that lead to misunderstandings on your guests' side. All explanations should be given on the homepage. (e.g. give hotel prices)
- **What you see is what you get ...**  
If you were your guest: What would you want to know ?  
Agenda, location, hotel, fee, language, childcare, medical needs ....
- Offer the possibility to register by email if necessary. Have an email form prepared for that.
- It is wise to offer a multilingual registration form online. This is not as complicated as it sounds.

Don't wait too long to spread the word! **Yes, this is repeated from before ...!!**

**The message should go out 1 year before the conference!**

Hopefully you can avoid other important events being planned the same days as „your“ chosen date.

Your visitors can plan their vacation in time

# Video conferences are so easy!



## Long before the conference

- **Plan carefully:**

Plenary sessions only??

Would breakout sessions be helpful?

Webinars? Parallel?

You need at least 1 host and co-host or other help for webinars.

You need at least 1 host and 2 or 3 co-hosts or other help for a huge plenary session. (Collect questions from the chat, answer technical questions ...)

- Have this planned into your agenda
- Book your simultaneous translators, make sure you can terminate the agreement at short notice before the conference.
- Ask patient representatives to be ready to translate the chat questions into English (or whatever is the main language).

## *3 months before the conference*

- **Check your registrations...**

Where do your guests come from? Send reminders with the hint that simultaneous translation can only be offered when enough people for a special language register. Set a date for the latest possible answer.

- Did you make contracts with translators? Now is the time to check whether you need all languages you ordered.

- International video conferences attract people from all over the world.

When planning the final agenda, try to think about the different time zones.

- Most speakers are better in the morning than in the middle of the night.

Many patients are interested to listen to speakers they can reach without travelling around the world.

# Video conferences are so hard!



## 4 weeks before the conference

- **Do you have planned some breaks between the sessions?**  
Keep breaks short (15 min) – people might leave and never come back otherwise.  
Think of a clear structure with clear times (e.g. CET). You will see people come and leave according to the time zones.
- Remind speakers to send their text or presentation in time, so the translators get a chance.
- Write clear announcements for all participants
  - how to log in
  - how to use a phone parallel to the meeting to hear the simultaneous translations (e.g. Speakus)

## 2 weeks before the conference

- **Offer a video meeting for as many speakers as possible.**  
Technical problems can be solved and the video tool explained.  
Ask them whether they want to show their slides on their own or the co-host should do it.
- **Have presenters send their slides in case their screensharing doesn't work!**
- **Do these tests with the translators as well!!**
- It is a good idea to send data protection information to everyone by mail before the conference, or put it on the website, so everyone can read it.

**Be sure: You can do it!!  
It will be the best conference ever!**



## **1 week before the conference**

- **Finalize the list of who is responsible for what.**
- Everybody has to know the flow of the conference and his / her place in it.
- Have you thought about some ice breaker games. Nobody really likes them, but they help to begin.  
Think about using polls instead or a little later during the sessions.
- Prepare a slide to ask participants to show their faces, their names.  
You cannot force them to do so, but a funny slide, shown once in a while might help here.
- **Do you want to record the sessions? You have to tell your participants when this starts and stops.**
- **The same with screenshots!**

## 2 days before the conference

- You will be busy doing all the things that didn't show up on a list in time.

## 1 day before the conference

- No one of your teams' families will talk to you any more .



Today it starts ...

It will be the best conference ever!



It will be **YOUR** conference!

Thank you very much for listening –  
even if I couldn't see you!!

Many thanks to Denise Dunne from CNE who read my slides  
and gave comments.

