



EURORDIS Membership Meeting

How to advocate with your
MP/MEPs – Tell a story

Dominique Sturz, Kostas Aligiannis

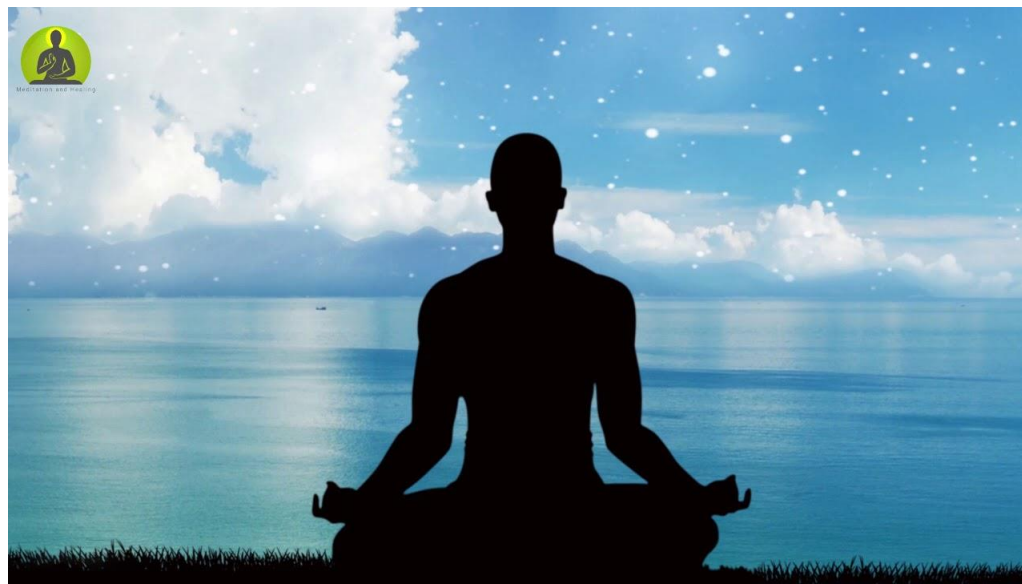
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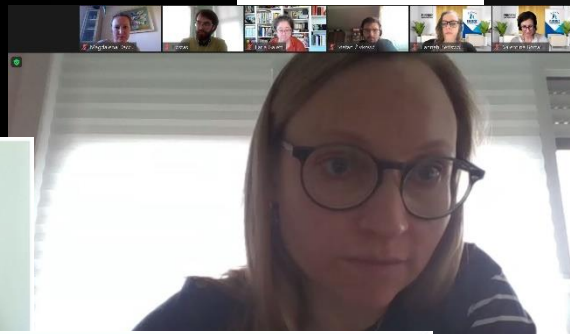
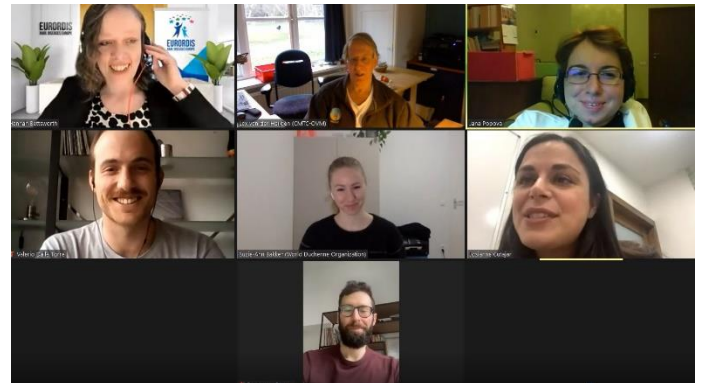
How can we work together to make engagements with policy-makers fun?



Why I got “infected” by the idea to join



Dominique Sturz
Pro Rare Austria
Disease area: Usher Syndrome



- Key challenges / barriers**
- | | | |
|--|--|---|
| <p>European level</p> <ul style="list-style-type: none"> Help from Think Tanks Contact our MPs and convince them of the need for national legislation and the impact on quality of life and the patient participation. European campaign with rare disease advocates Ask EURORDIS for help :) Study visits - best practices Ask the EU Commission for funding of the European Rare Disease Research and Innovation Programme Secure umbrella organisations for rare diseases - first to gather all those around the same table and together think what is the role and the message to send to the national representatives and offer that to the Finnish MPs. Ask the ERD coordinator to publish the first results including Patient representatives on all levels of | <p>Iaria - bring good practice where NDS is already implemented and has a positive impact on quality of life and the patient participation.</p> <ul style="list-style-type: none"> Support the national small rare disease associations contact representatives. reach out to national government Suzie Ann - use NDS principles within your own TD area and have working groups of different countries bring case study/personal story / other evidence demonstrating benefit for patient and health system publish data to support any | <p>National level</p> <ul style="list-style-type: none"> Letter to the national representative in the council Working group formation to develop successful case study Ask the National rare disease umbrella organization for support reach out to national government through national level try and understand first what the national level can do and address them country level |
|--|--|---|



Rare Disease Week in Brussels



Main objectives are

- ★ **Raise Awareness on RDs** with MEPs and other policy-makers
- ★ Engage + expand [Network of Parliamentary Advocates for Rare Diseases](#) once/year
- 3. ★ Empower participants with **knowledge about advocacy in Brussels** – > take back home
- 4. ★ Establish **EU/national network of people who can readily participate in advocacy campaigns** carried out in Brussels



The game of three



What interest do they represent?

- The **European Commission** represents the interests of the EU as a whole.
- The **European Parliament** represents the interests of European Citizens.
- The **Council of the European Union** (“Council or the Council of Ministers”) represents the member state governments

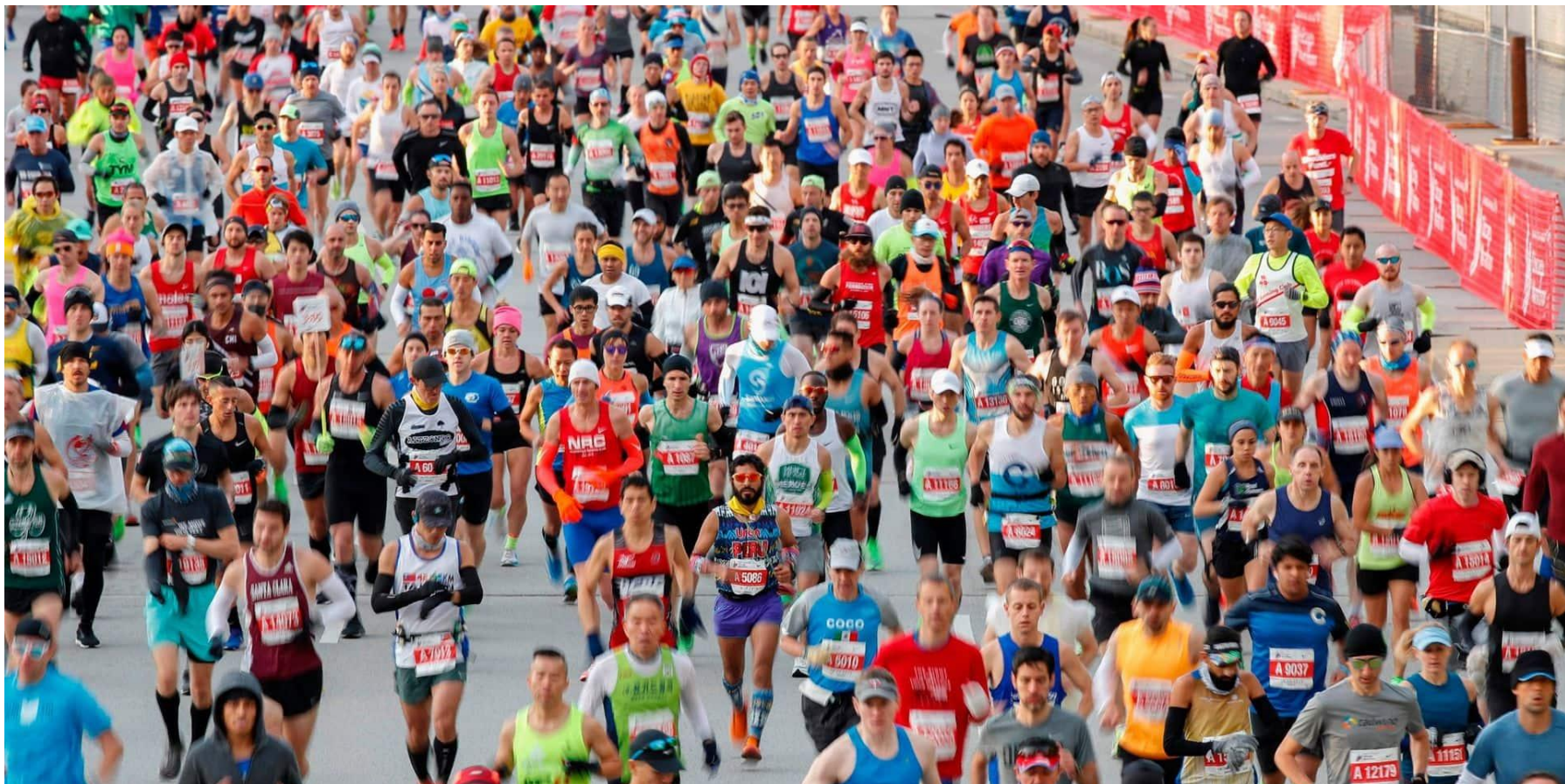
HTA

- **H**ea**l**th **T**echnology **A**ssessment;
- HTA evaluates new technologies (medicines, medical devices, diagnostic methods, etc.) compared to existing ones;
- Very similar assessments are made in most of the EU member states;
- Commission proposes to conduct a part of the assessment at European level to avoid duplication and waste of resources.

Health
Technology
Assessment
(HTA)



Advocacy, probably not a sport but...



... definitely a competition!

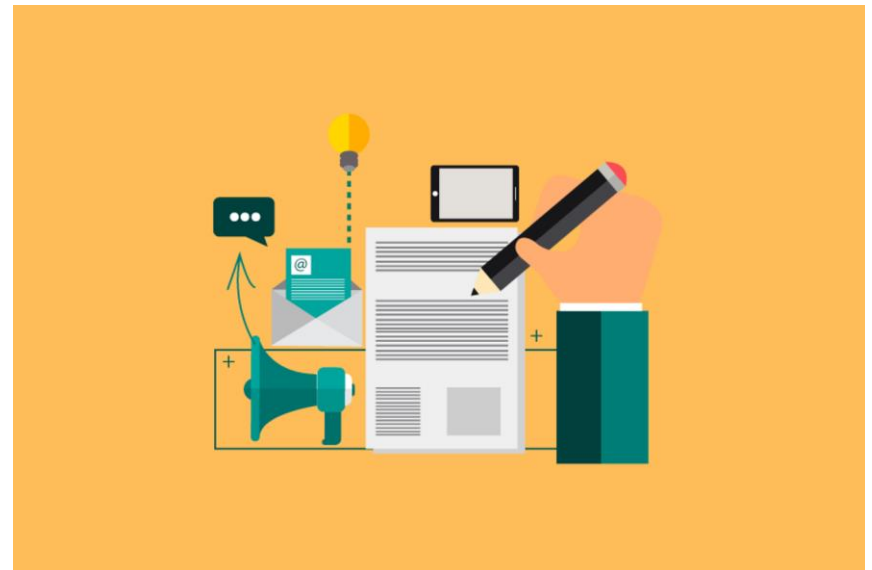
- European Commission staff (civil servants & contracts): 33.000 pers.
- Including European Parliament, Council, agencies... : 60.000 pers.
- Diplomats: 5.000 pers.
- Lobbyists: between 20.000 and 25.000 pers.
- Journalists: 1.000 pers.

➡ 14% of Brussels GDP in 2011!

(source: Bureau de liaison Bruxelles Europe)

3 c elements

- Competences
- Content
- Captivate



Find a way to impress



SOFT SKILLS: Which ones?

- 1. Communication** – oral speaking capability, written, presenting, listening, clear speech & writing.
- 2. Courtesy** – manners, etiquette, business etiquette, gracious, says please and thank you, respectful.
- 3. Flexibility** – adaptability, willing to change, lifelong learner, accepts new things, adjusts, teachable.
- 4. Integrity** – honest, ethical, high morals, has personal values, does what's right.
- 5. Interpersonal skills** – nice, personable, sense of humor, friendly, nurturing, empathetic, has self-control, patient, sociability, warmth, social skills.

SOFT SKILLS: Which ones?

6. Positive attitude – optimistic, enthusiastic, encouraging, happy, confident.

7. Professionalism – businesslike, well-dressed, appearance, poised.

8. Responsibility – accountable, reliable, gets the job done, resourceful, self-disciplined, wants to do well, conscientious, common sense.

9. Teamwork – cooperative, gets along with others, agreeable, supportive, helpful, collaborative.

10. Work ethic – hard working, willing to work, loyal, initiative, self-motivated, on time, good attendance

(Source: ECU M Roblès)



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