

# **Open Discussions/New Issues Forum/ Future Emphasis of ICORD Meetings**

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# How to develop ICORD further?

- We have established an international forum for
  - Patient group representatives
  - Society representatives (including regulators)
  - Industry representatives
  - .. but Academia representatives are to few

# Academia is important in RD

- Most RD development comes from Academia
  - Identifying new disease mechanisms
    - Identifying new possible drugs
    - Developing new drugs (often with Industry)
  - Improving therapy with old drugs
    - Clinical trials with known drugs
  - Improving diagnostics
    - So that treatment can start earlier
  - Improving patient monitoring

# How to get Academia into ICORD

## Make ICORD a Large Rare Disease Forum!

- Maybe family organisations can arrange Scientific Society Annual Meetings at ICORD!
  - Provides access to physicians, new therapy and research
  - Provides support for academic clinical trials
  - In addition maybe one common day for all Societies
    - Statistical lectures
    - Clinical trials support, ethical applications, FDA/COMP
- Industry will get access to many meetings in one
- Regulators get close to researchers and industry
- Family organisations can meet and teach each other

# Future Opportunities

Make ICORD a Large Rare Disease Forum!

- Assist Academia to arrange Meetings here
- Assist Academia in running clinical trials
  
- A Vision – but maybe only a Dream