



Cystinosis Network Europe

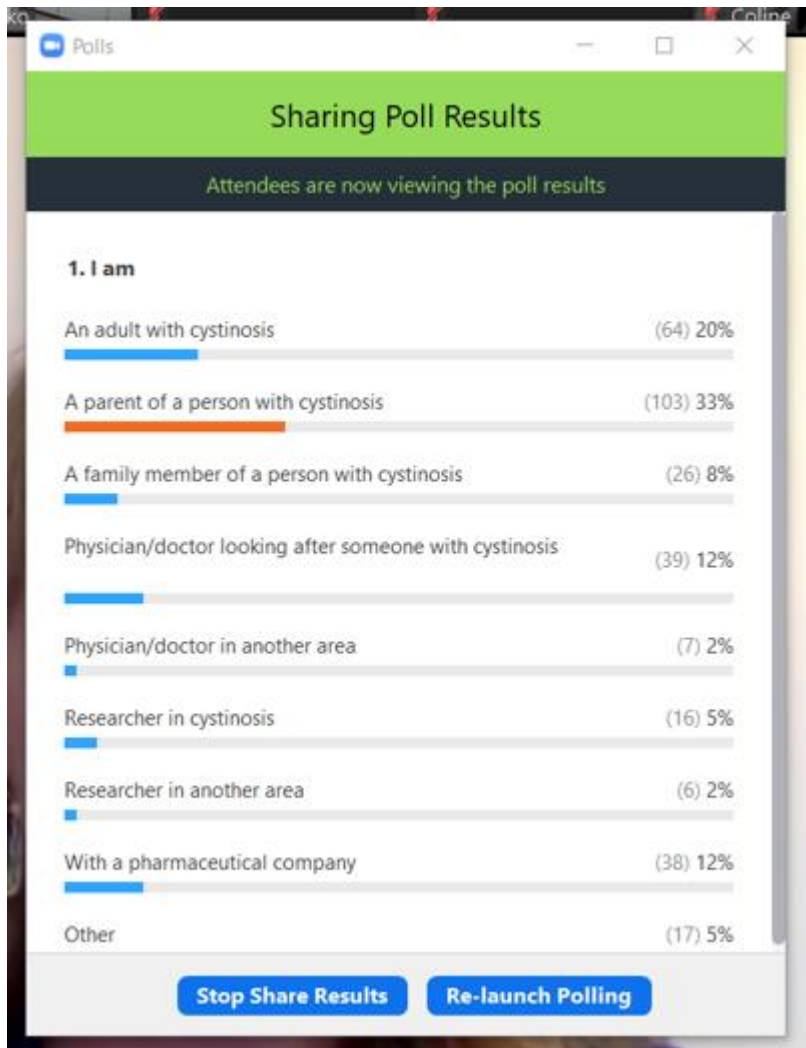
2020 In Review

International Conference

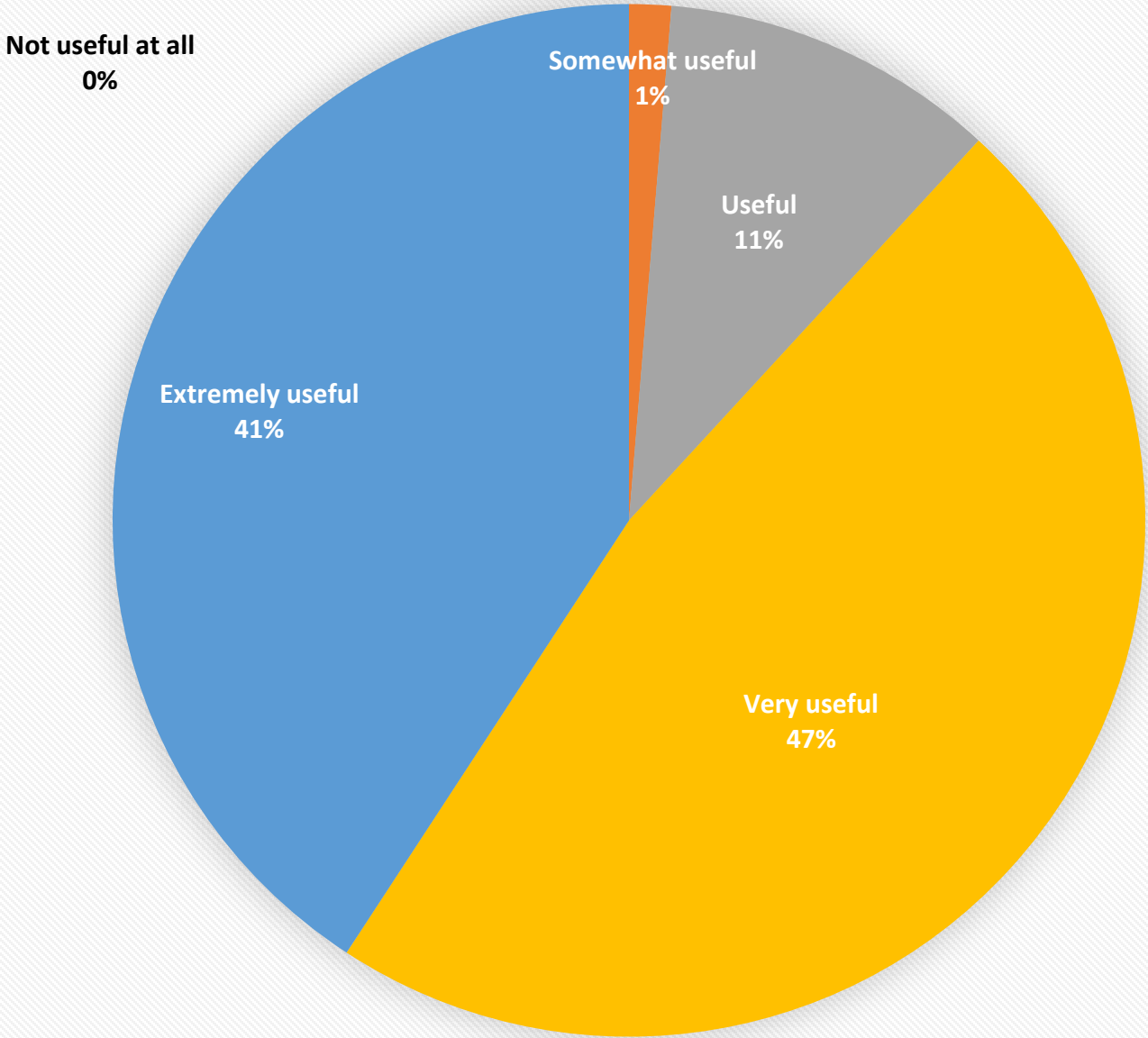
- Conference originally planned for July in Dublin but due to corona virus was moved to a virtual event on 29 April
- Key facts:
 - more than 600 participants
 - 49 different countries
 - 20 time zones across the world
 - Simultaneous translation into 7 languages
 - Presentations from 16 world renowned clinicians, researchers and other healthcare professionals



Who attended?



What did they think of the conference?



■ Not useful at all ■ Somewhat useful ■ Useful ■ Very useful ■ Extremely useful



Community Advisory Board

- Working with Chiesi, Avrobio for meetings
- Ongoing contact with Recordati
- Contact with research groups including K Hohenfellner; A Chauhan; H Newell



Membership

- Ireland (Chair, board member & secretariat)
- Germany (Board member)
- Netherlands & Belgium (Board member)
- France
- Italy
- Spain
- UK

Associate members

- USA
- Australia
- South Africa

Prospective Members

- *Turkey*
- *Russia*
- *Mexico*



Governance

- Cystinosis support Network Europe established in Dublin, Ireland
- Board members: Anne Marie O'Dowd (Ireland, Chair), Claudia Sproedt (Germany), Marjolein Bos (Netherlands), Niamh O'Brien (Ireland, Treasurer), Denise Dunne (Ireland, company secretary)

