From basic research to clinical trials and EB care – what DEBRA can do for patients
Who is DEBRA

• DEBRA UK, first group – founded about 40 years ago
• DEBRA Europe – started 25 years ago
• DEBRA International – founded 2007

• Network with about 50 member groups around the globe
• Representing approx. 1 Mio patients
• Exec Committee – 10 members out of 10 countries
• DEBRA International (patient) conference - yearly
  – 2017: New Zealand, Wellington, November 24-27
  – 2018: Switzerland, Zermatt Video: Introduction to PPI
DEBRA’s roles – ‘Glue’, ‘Catalyst’
What DEBRA groups offer

• Range of support for research and community

  ➢ International research

  ➢ Clinical guidelines

  ➢ Clinical trials

  ➢ EB care

  ➢ Collaboration
What DEBRA groups offer 1/3

- International research
  - DI research strategy
  - Basic research (‘all priorities’)
  - (Pre)Clinical research
  - Symptom relief → Wound care, Cancer, inflammation, fibrosis
  - 2 yearly calls (yearly spent 1 – 3 Mio Euro)
  - Peer reviewed applications (15 – 25 / year)
  - Online grant management system (CC grant tracker)
  - Collaboration between DEBRA groups in terms of funding and admin
  - Approx. 30 Mio Euro spent to date

- DEBRA International Research Involvement Network
What DEBRA groups offer 2/3

• Clinical trials
  – Financial support for studies which do not attract bio-tech / pharma
  – Registries (ERN skin – OpenApp)
  – Information to the membership / patients
  – Glue / catalyst: sponsor, clinicians, regulatory agencies
  – Training: EURORDIS summer school / EUPATI
What DEBRA groups offer 3/3

• EB care
  – Support for clinical centers
  – Funding for nurses, psycho-social support
  – Healthcare at home
So fühlts sich das Leben für ein Schmetterlingskind an.

Schmetterlingskinder leiden an einer unheilbaren, schmerzvollen Hauterkrankung. Bitte spenden Sie unter schmetterlingskinder.at

Thank you