

So fühlt sich das Leben für ein Schmetterlingskind an.

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




debra
Hilfe für die Schmetterlingskinder.

Übertraglicher Ausweg durch Epinevris - Europäische Patent- und Anwaltskanzlei GmbH

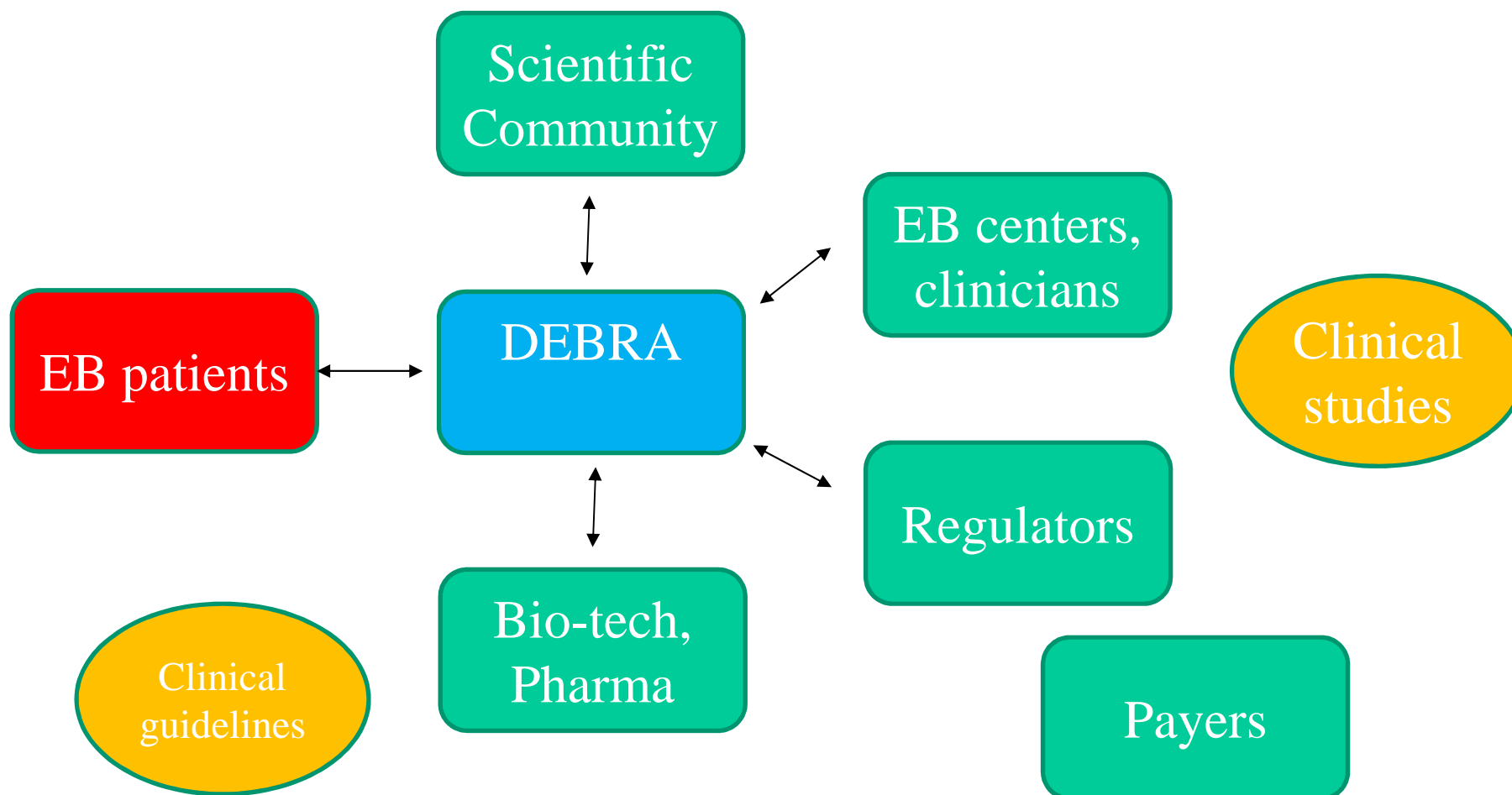
**From basic research to clinical trials and
EB care – what DEBRA can do for patients**

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

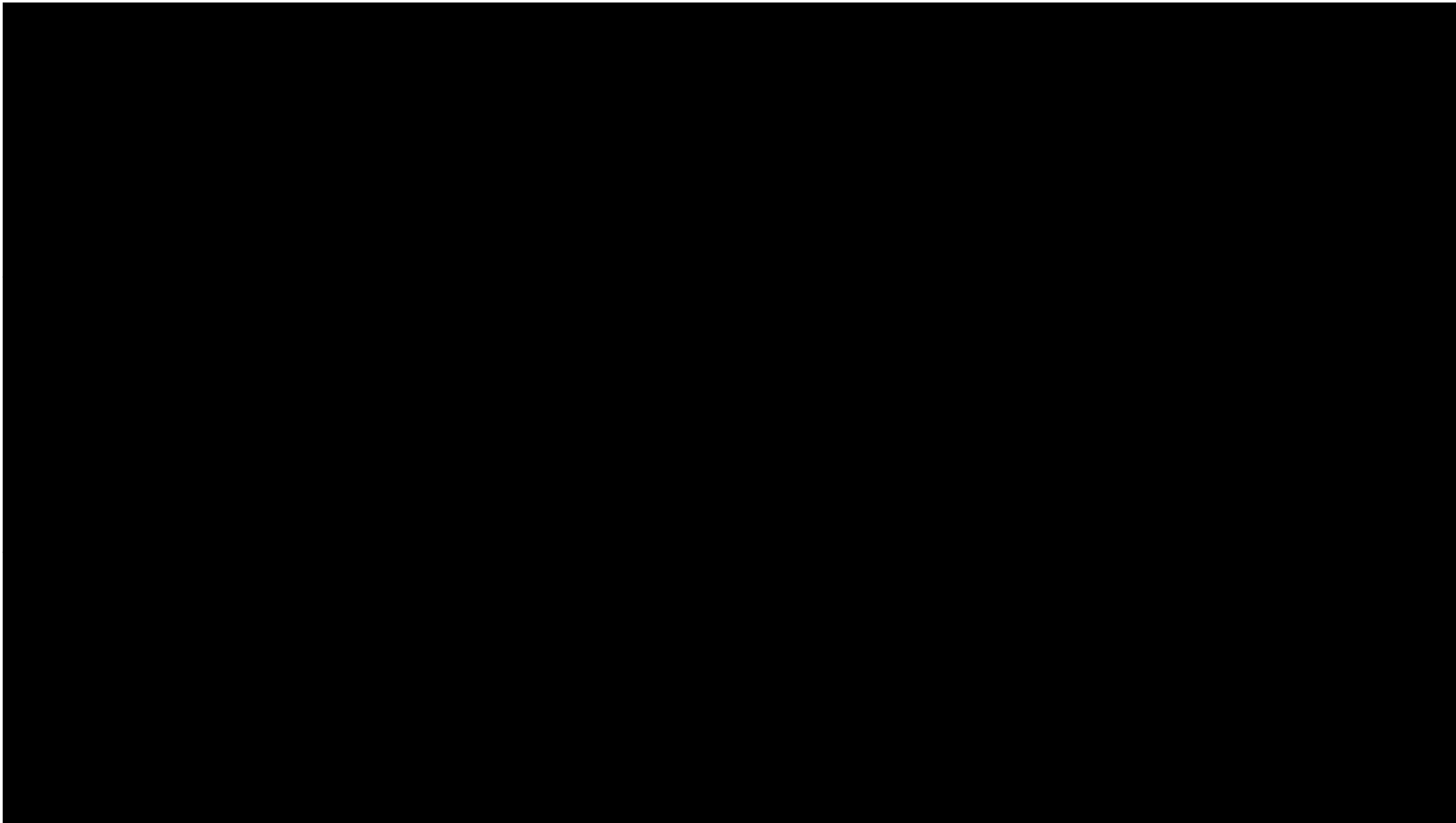
- International research
 - DI research strategy
 - Basic research ('all priorities')
 - (Pre)Clinical research
 - Symptom relief → Wound care, Cancer, inflammation, fibrosis
 - 2 yearly calls (yearly spent 1 – 3 Mio Euro)
 - Peer reviewed applications (15 – 25 / year)
 - Online grant management system (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
<http://bit.ly/DEBRAInternationalRIN>

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



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Übergelieferter Auftrag durch Epimedis - Europäische Plastik- und Kunststoffwerke GmbH

Thank you