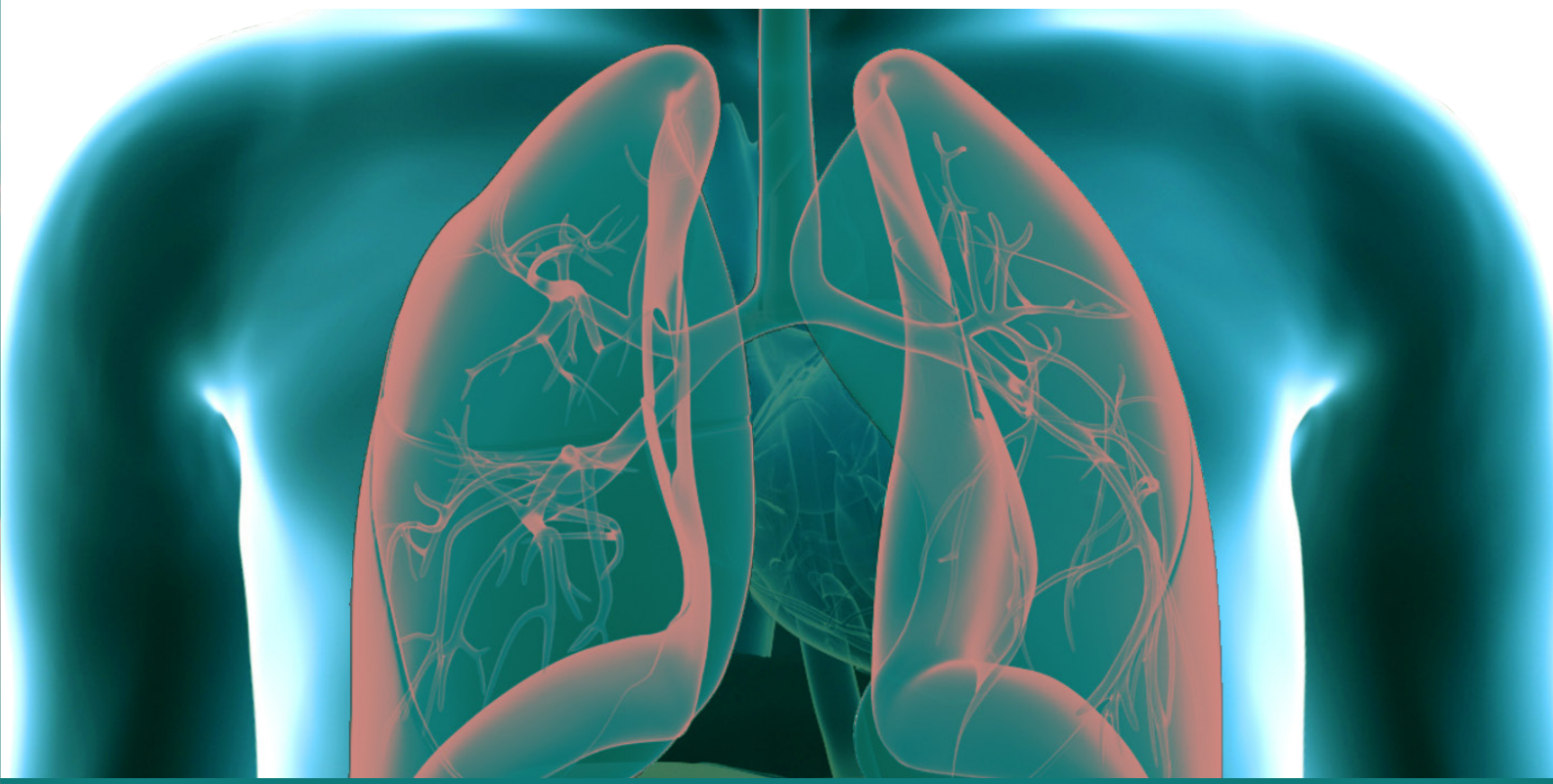
Organo ufficiale della Società Italiana per le Malattie Respiratorie Infantili (SIMRI)
Official Journal of the Italian Society of Pediatric Respiratory Diseases

PNEUMOLOGIA PEDIATRICA

Le malattie Interstiziali polmonari in età pediatrica (chILDs)



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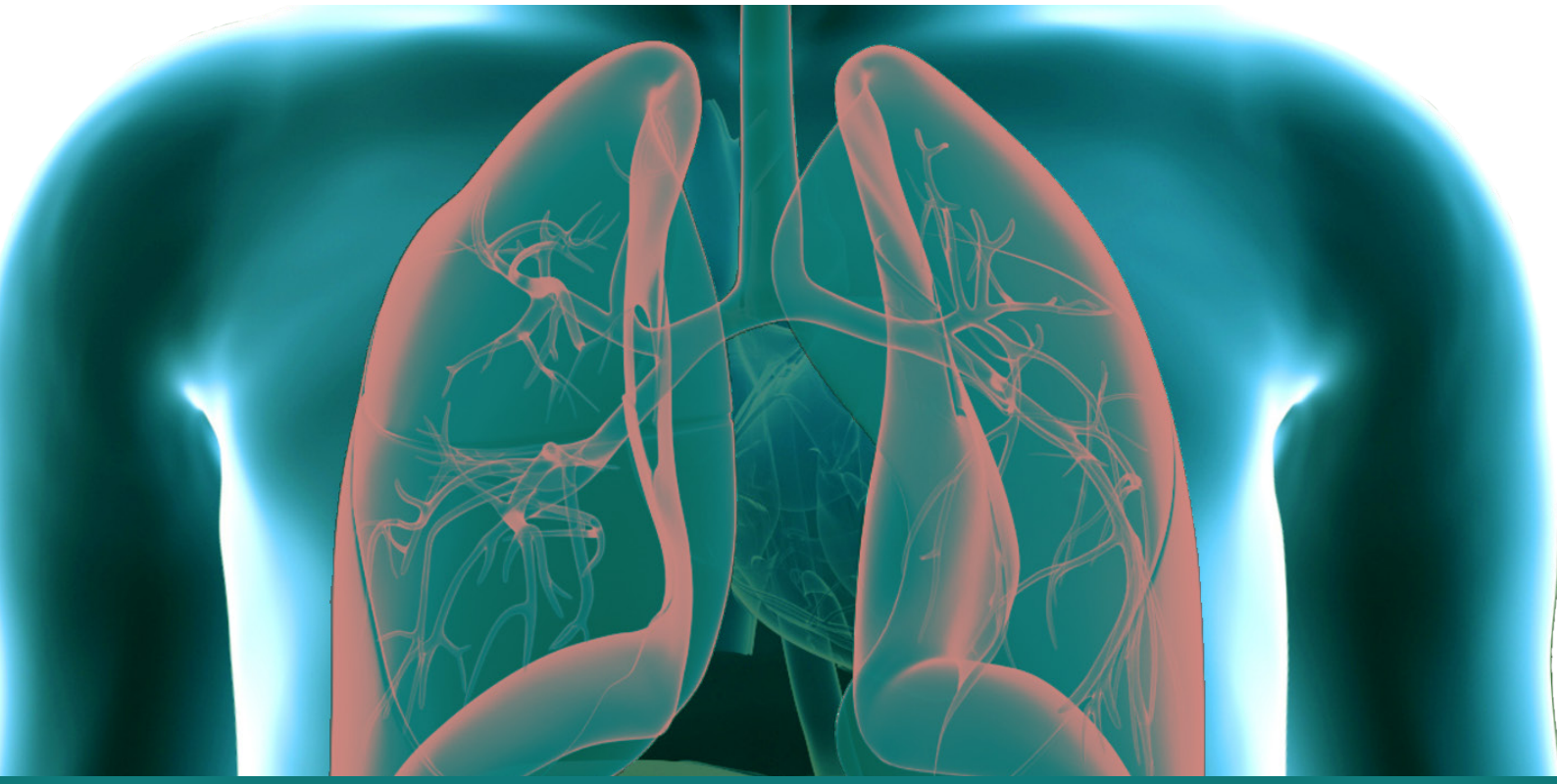
HIGHLIGHT FROM PRAGUE

International metting cost



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CHILD-EU
Orphans Unite: chILD better together
European Management Platform for Childhood Interstitial Lung Diseases

Deborah Snijders on behalf of prof Matthias Griese

Corrispondenza: deborah.snijders@unipd.it

Childhood interstitial lung diseases (chILD) are rare disorders which comprise a large group of childhood specific entities as well as the spectrum known from the adult ILD. There are many unmet needs in this orphaned area. Ten major ones have been addressed in the FP7 chILD-EU project.

1. *Low diagnostic awareness for chILD and isolated treatment across Europe*

European clinicians caring for isolated orphan cases of chILD were united into a critical mass of expertise that no individual Country can provide. The European management platform for chILD is open to all caregivers interested, both professionals and lay people. For policy makers, our results point to a significant population in need for more support.

2. *Missing of a pan-European database and bio-bank compatible with others worldwide*

ChILD-EU has successfully implemented a web-based data capture and biobank system running on SecuTrial®. After notification via www.childeu.net, the participant is registered, trained and supported to enter pseudonymized patient data and submit biomaterials to the central site. Patient data entry started in 2014. By November 2016, 575 cases from more than 100 sites in Germany, UK, Turkey and many other Countries have been included.

3. *Lack of verification of diagnoses by multidisciplinary expert panels*

After being appropriately entered, those cases ready for international multidisciplinary team peer-review were reviewed by clinical experts, pediatric radiology experts, and if necessary specialized pathology and genetic experts. By November 2016, 363 cases are finally reviewed and followed prospectively.

4. *chILD-EU has generated a "Best practice Checklist"*

For the diagnostics in suspected chILD and compiled "Standard Operating Procedures (SOPs)" based on the results of collected current clinical practice in Europe.

5. *Prospective observational data on incident and prevalent chILD cases*

chILD-EU actively pulled together currently isolated cases of chILD into a critical mass of patients that will enable prospective evaluation of the clinical, radiological and prognostic course.

6. *Central biomaterial repository for long term storage of samples*

We opened a web based biobank which can be followed on line and used for well characterized patients to elucidate the mechanisms of these rare diseases.

7. *Involvement of affected families and patients*

chILD-EU assessed family experience with chILD and identified up to now unrecognized and unmet needs, like feeding issues. Patient's care was directly assessed and improved by development of a freely available patient information booklet. This was produced in German, French, Danish, Turkish, Italian and English.

8. Quality of life and health economics

Disease specific patient reported outcomes have been developed and validated. Patients´ health economics and patient reported outcomes have been assessed in chILD for the first time, helping to improve the quality of life for children and their parents.

9. Clinical outcomes and lack of knowledge on currently used treatments

Following several rounds of discussion and document evaluation among the participants, key parameters for outcome follow-up were defined. The complex variable acute exacerbation was defined, and criteria for evaluation were suggested. Designs to evaluate chest imaging and histology were proposed.

10. Lack of randomized and controlled interventions with off-label treatments

After a world-wide Delphi process to reflect on the needs and wishes of the community, we decided to focus on the investigations of two compounds, i.e. hydroxyl-chloroquine and systemic steroids. Three randomized, placebo controlled trials were designed and initiated in Germany. In summary, the project successfully implemented a pan European management platform for chILD as a solid base for future clinical and research networks. At the moment, the chILD-EU register is still open for patient recruitment and, together with the COST Action ENTeR-chILD, new initiatives have been developed to keep high the interest in chILD.