



Evidence based medicine and research in rehabilitation of childhood disabilities: a course on research in child rehabilitation and good clinical practice

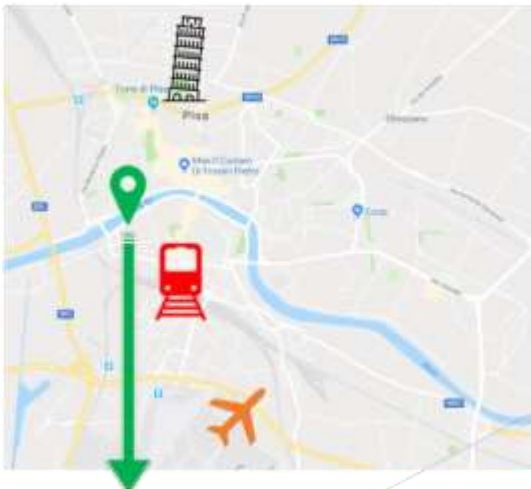
Coordinator: Prof. Giovanni Cioni
Department of Clinical and Experimental Medicine, University of Pisa
and IRCCS Fondazione Stella Maris

CENTRO CONGRESSI LE BENEDETTINE
Pisa
July 15-19, 2019

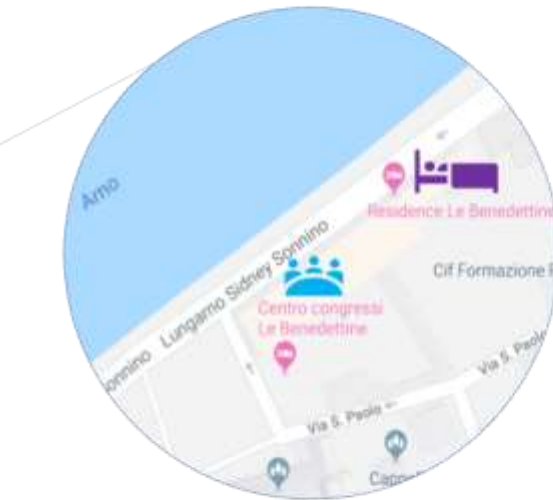
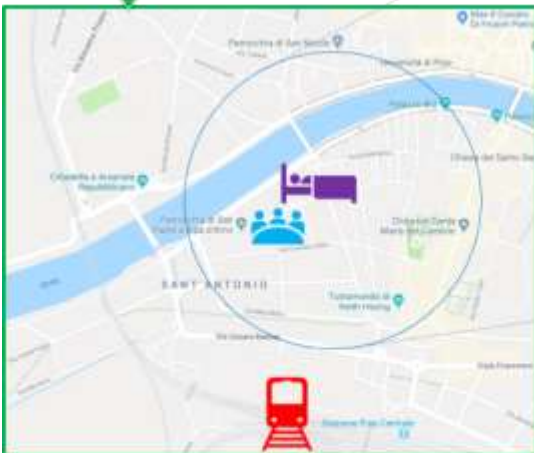
PROGRAMME

Summer School Venue

Centro Congressi Le Benedettine, Piazza S. Paolo a Ripa D'Arno, 16, 56125 Pisa, Italy



 **Residence le Benedettine**
Lungarno Sidney Sonnino, 18, 56125 Pisa PI



 **Centro congressi le Benedettine**
Piazza S. Paolo a Ripa D'Arno, 16, 56125 Pisa PI



The Centro Congressi Le Benedettine of the University of Pisa is easily reachable from the airport (10 min by taxi) and from the railways station (10 min walking). Public transportation (Pisa Mover and buses) is also available. Most of the participants and tutors will be hosted by Residence Le Benedettine, (Lungarno Sonnino 18, Pisa, Italy) in the same building of the Centro Congressi, whose entrances are indicated in the map.

Monday July 15

Patient and family-centred research – identifying a research question together.

Tutors: **Em. Prof. Jules Becher**, MD, PhD, *Amsterdam (The Netherlands)*
Karen van Meeteren, Experienced expert, *Weesp (The Netherlands)*

8.00-8.30 Registration

8.30- 9.00 Welcome address
Prof. Paolo Mancarella, Rector of the University of Pisa
Welcome, goals of the Summer School
Prof. Giovanni Cioni, Chair of the EACD and Coordinator of the Summer School

9.00-9.30 Introduction of the participants

9.30-10.30 Why should you involve clients or family in clinical research?
Questionnaire, discussion

10.30-11.00 Coffee break

11.00-11.30 Tools for client engagement: the participation matrix

11.30-12.30 Theory and practising the technique for asking the needs

12.30-13.30 Lunch

13.30-14.15 The ICF-CY model for treatment in childhood disability and the F-words

14.15-15.00 Instruments for patient reported outcome measures (PROM): COPM, GAS, Likert scales, questionnaires, HRQOL

15.00-15.30 Coffee break

15.30-16.15 Practice: identifying ICF-CY domains of aims of a study and outcome measures. Which problems for the client will be solved?

16.15- 16.30 The PICO method to define clinical research proposals

16.30-17.10 Defining a clinical research question and client engagement

17.10-17.30 Break

17.30-18.10 Lecture: A general concept for treatment and clinical research
Jules Becker

18.10-18.45 Closing Lecture: Early intervention in high-risk newborns: the VISIBLE project
Andrea Guzzetta (Pisa)

Tuesday July 16

From research question to research proposal – methodological issues in childhood disability research.

Tutors: **Prof. Hans Forssberg**, MD, PhD, *Stockholm (Sweden)*
Juliet Goldbart, PhD, *Manchester (United Kingdom)*

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| 8.30- 10.00 | Quantitative research methods for stating research questions in research proposal
<i>Hans Forssberg</i> |
| 10.00- 10.30 | Students presentations |
| 10.30-11.00 | Coffee break |
| 11.00-12.30 | Open presentations and discussions |
| 12.30-13.30 | Lunch |
| 13.30-15.00 | Qualitative research methods in neurodisability
<i>Juliet Goldbart</i> |
| 15.00-15.30 | Coffee break |
| 15.30-17.00 | Practice |
| 17.00-17.15 | Wrap-up of the day |
| 17.15-17.45 | Break |
| 17.45-18.30 | Meet the researcher: From Gut to Brain in autism spectrum disorder
<i>Elisa Santocchi (Pisa)</i> |

Wednesday July 17

The childhood disability research toolbox – instruments and measurements in neurodevelopmental and rehabilitation science.

Tutors: **Prof. Ann-Christin Eliasson**, OT, PhD, *Stockholm (Sweden)*
 Dr. Arnab Seal, MD, *Leeds (United Kingdom)*

- 8.30- 8.45 Outline of day
 Discussion: what would attendees want out of the day
 Ann-Christin Eliasson and Arnab Seal
- 8.45- 9.15 What do people want to know about? Global Knowledge Translation and implications for research: Professionals' knowledge priorities (2016 IAACD Survey) and Parents' research priorities
 Arnab Seal
- 9.15- 10.30 The Toolkit of Foundational concepts: the principles underpinning 21st century practice: Lecture with buzz sessions and small group workshop
 Arnab Seal
- 10.30-11.00 Coffee break
- 11.00-12.30 Choosing the right tools for different questions: Lecture and group session
 Ann-Christin Eliasson
- 12.30-13.30 Lunch
- 13.30-14.30 How to develop an assessment tool (using the MACS example)
 Ann-Christin Eliasson
- 14.30-15.00 Discussion on implications for your own research: small group session
 Ann-Christin Eliasson and Arnab Seal
- 15.00-15.30 Coffee break
- 15.30-16.00 Goal setting in practice: small group workshop
- 16.00-16.30 Feedbacks from groups
- 16.30-17.30 Implication for research
- 17.00-17.15 Feedback & discussion session: key learning from the day
 Ann-Christin Eliasson and Arnab Seal
- 17.15-17.45 Break
- 17.45-18.30 Meet the researcher: New neurophysiological approaches to treatment of children with hemiplegia
 Giuseppina Sgandurra (Pisa)

Thursday July 18

Good clinical practice in childhood disability research – fostering the credibility, scientific and ethical quality of your research.

Tutors: **Prof. Bernard Dan, MD, PhD, *Brussels (Belgium)***

8.30- 10.30	Good clinical practice in childhood disability research <i>Bernard Dan</i>
10.30-11.00	Coffee break
11.00-12.30	Working group
12.30-13.30	Lunch
13.30-14.30	Departure and arrival to Stella Maris Institute
14.30-16.00	Presentation of Stella Maris research and laboratories
16.00-18.00	Visit to the main Stella Maris research laboratories
18.00-20.00	Free time
20.00-22.00	Social dinner
22.30	Return to Pisa

Friday July 19

My career in childhood disability research – a look towards the future based on the week's experiences.

Tutors: **Dr. Christopher Newman**, MD, PhD, *Lausanne (Switzerland)*
 Dr. Miklós Lászlo Györffi, PhD, *Brussels (Belgium)*

- 8.30- 09.00 Welcome – students' experiences with funding, a roundtable
- 09.00-10.30 Funding your research – European opportunities
Miklos Gyorffi
- 10.30-11.00 Coffee break
- 11.00-12.30 A career in childhood disability research – hard skills and soft skills
Christopher Newman
- 12.30-13.30 Lunch
- 13.30-15.00 The grand call – a group simulation
- 15.00-15.30 Coffee break
- 15.30-16.30 The grand call – group presentations
- 16.30-16.45 A final exercise – back to the future
- 16.45-17.00 Evaluation form
- 17.00-17.30 From Summer School to future researches
Giovanni Cioni

Coordinator

Giovanni Cioni, *University of Pisa and IRCCS Fondazione Stella Maris (Pisa)*

Organizer

Giuseppina Sgandurra, *University of Pisa and IRCCS Fondazione Stella Maris (Pisa)*

Scientific Committee

Jules Becher (*Amsterdam*), Bernard Dan (*Brussels*), Christopher Newman (*Lausanne*)

Tutors

Jules Becher, *Free University of Amsterdam, Amsterdam, The Netherlands*

Bernard Dan, *Université libre de Bruxelles, Brussels, Belgium*

Hans Forssberg, *Karolinska Institute, Stockholm, Sweden*

Juliet Goldbart, *Manchester Metropolitan University, Manchester, United Kingdom*

Miklós László Györffi, *European Parliament, Brussels, Belgium*

Ann Christin Eliasson, *Karolinska Institute, Stockholm, Sweden*

Karen van Meeteren, *Experienced expert, Weesp, The Netherlands*

Christopher Newman, *Centre hospitalier universitaire Caudois, Lausanne, Switzerland*

Arnab Seal, *Leeds Community Healthcare NHS Trust, Leeds, United Kingdom*

Lecturers

Andrea Guzzetta, *University of Pisa and IRCCS Fondazione Stella Maris, Pisa, Italy*

Elisa Santocchi, *IRCCS Fondazione Stella Maris, Pisa, Italy*

Giuseppina Sgandurra, *University of Pisa and IRCCS Fondazione Stella Maris, Pisa, Italy*

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