

FRIDAY 16th SEPTEMBER: RESEARCH COLLABORATION EVENT

Ghent University Hospital

Corneel Heymanslaan 10 – Gate 38

08:00-09:00 REGISTRATION and COFFEE

09:00-09:15 OPENING RESEARCH COLLABORATION EVENT

Prof. Dr. Bert Callewaert: goals of the collaboration event:

- *The current research landscape in cutis laxa*
- *Challenges for research in extremely rare disorders*
- *Leveraging (international) collaboration in cutis laxa research*
- *Including patient perspectives in cutis laxa research*
- *Setting forward short and longer term goals in research on cutis laxa*
- *Funding acquisition in an international context*

09:15-10h45 WORKING GROUP CLINIC & RESEARCH

Oral presentations of early career scientists

10:45-11:15 COFFEE BREAK

11:15-12:45 WORKING GROUPS

WORKING GROUP CLINIC & RESEARCH	WORKING GROUP PATIENT ADVISORY BOARD
<ul style="list-style-type: none">- <i>Inventory of available expertise</i>- <i>Inventory of ongoing research projects: sharing knowledge</i>- <i>Establishing a nosology and guideline working group and working protocol</i>- <i>Establishing an 'ad hoc' disease specific clinical care group</i>- <i>Interoperability of local databases and biobanks</i>- <i>Repurposing international initiatives such as Genematcher and Variantmatcher in a disease-specific umbrella.</i>- <i>Identifying future research collaborations</i>- <i>Planning funding acquisition (innovative training networks, cost actions, ...)</i>	<ul style="list-style-type: none">- <i>General discussion of the results of the focus groups and the patient journeys</i>- <i>Identifying the major disease burdens</i>- <i>Identifying and formulating future needs research & care</i>- <i>Identifying hinge points for patient advocacy in research</i>- <i>Identifying opportunities for patient to involve in funding acquisition</i>

12:45-14:00 LUNCH & NETWORKING

14:00-15:00 WORKING GROUP CLINIC & RESEARCH *Continued*

WORKING GROUP PATIENT ADVISORY BOARD *Continued*

14:00-15:00 ROUNDTABLE AND DISCUSSION

Report from the working group clinic and research (10')

Report from the working group patient advisory board (10')

General discussion – future meeting