

Programme for the NBIA Family Conference 2014 in Germany

Start: Friday, May 2nd, 9.00

End: Sunday, May 4th, 12.00

Thursday, 1st May

until 17.30	Arrival of families, Hotel registration
18.00	Dinner
19.30-20.30	Attunement "Living with NBIA" – a stony way

Friday morning, 2nd May Living with NBIA – the medical side

from 7.30	Breakfast
8.30- 9.00	Conference registration
9.15	Conference Opening: Organization / Introduction conference programme Angelika Klucken, Hoffnungsbaum e.V.
9.30-12.30	Parallel: child and youth care
9.45	Therapies for NBIA disorders  Dr. Ivan Karin, Department of Neurology of the University hospital Munich, Friedrich-Baur-Institute
10.30	The NBIA research project TIRCON: Patient registry and trial  Dr. Borianna Büchner, Department of Neurology of the University hospital Munich, Friedrich-Baur-Institute
11.15-12.45	Parallel: Individual counselling regarding NBIA patient registry 
11.15-11.45	Coffee break
11.45	News from NBIA-diagnostics and TIRCON biobank  Caroline Biagosch, Technical University Munich, Institute for Human Genetics
12.30	Group picture
12.45	Lunch



Hoffnungsbaum e.V.

Friday afternoon, 2nd May	
Living with NBIA – the social side	
14 - 17.00	Parallel: child care
14.00	Deep brain stimulation and NBIA – What is new? Dr. Amade Pauls, Department of Neurology at the University Hospital Cologne
15.00	Coffee break
15.30	News from social legislation in Germany Evelyn Küpper - Lebenshilfe Düsseldorf e.V. Mrs Küpper is available for families' individual counselling if required.
17.00	Free time Board Meeting Hoffnungsbaum e.V. Attendees: Board members
18.00	Dinner
20.00	Free time

Saturday morning, 3rd May	
Living with NBIA – participate in social life	
7.30	Breakfast
9.00-12.30	Parallel: child care / special offer for siblings of pedagogue (Manuel Spors)
9.00	My disabled child attains full age Evelyn Küpper - Lebenshilfe Düsseldorf e.V.
10.30	Coffee Break
11.00	Family support and assistance for leisure time - Exchange of experiences Impulse: N.N.
11.45	Talker 2.0? Computer-assisted communication with i-pad, i-phone & Co. Stephan und Angelika Klucken - Hoffnungsbaum e.V.
12.30	Lunch

Saturday afternoon, 3rd May	
Living with NBIA – the patient advocacy	
14-17.00	Parallel: child care / special offer for siblings of pedagogue (Manuel Spors)
14.00	General meeting and board elections of Hoffnungsbaum e.V. (incl. Hoffnungsbaum and TIRCON annual report) Angelika & Stephan Klucken, Hoffnungsbaum e.V.
15.15	Rare Connect & Co. –opportunities to exchange experiences for NBIA families Heike Jaskolka, Hoffnungsbaum e.V.

15.45	Commemoration Ceremony
16.00	Coffee Break
16.30	The craniosacral therapy Walburga Steiner, Natural health professional and craniosacral therapist, Hohenroda
18.00	Dinner
19.30	Social evening: Singing, playing, chatting

Sunday, 4th May Living with NBIA – the patient advocacy – how to continue?	
7.30	Breakfast
9.00-10.30	Parallel: child care
9.00	Hoffnungsbaum e.V. – What is the outlook into the future? Round of talks
10.00	Exchange of research and care / Patient survey on supply of remedies
10.30	Coffee break
11.00	Closing ceremony: Living with NBIA – What do we take with us?
12.00	Lunch
afterwards	Departure

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