# WELCOME NOTE

# REGISTRATION AND ACCOMMODATION





#### Dear Colleagues, Patients and Caregivers,

We are pleased to invite you to the  $9^{th}$  International Meeting on Neuroacanthocytosis Syndromes which will take place in Dresden, Germany, March 23–25, 2018. It follows the previous 8 international symposia, the last of which was held in Ann Arbor, USA in May, 2016.

Neuroacanthocytosis Syndromes are a group of rare neurological disorders. Chorea Acanthocytosis is the "core" disease of this family caused by mutations in the VPS13A gene encoding for chorein. As a neurodegenerative disease it leads to chorea, epilepsy, problems with mood, thinking and memory, and acanthocytosis of red blood cells. At present there are no treatments that can halt or slow down the progression of these diseases; however, our research continues to move in the direction of possible therapies.

The objectives of this meeting are to bring together basic and clinical neuroscientists and neurologists to address new discoveries in this expanding field. There will be a particular focus on important developments in basic science since 2016, in addition to the potential clinical translation of experimental treatments developed in vitro.

We encourage young faculty and students to present their work for example during the poster session.

Patients and caregivers continue to play a critical role in this process, as we will discuss together the next steps, action points, and future studies. This is a collaborative process involving researchers, clinicians, patients, and caregivers, in our quest to advance knowledge and practice. As always, the Advocacy for Neuroacanthocytosis Patients is playing a crucial role in determining our goals.

We are looking forward to welcoming you in Dresden, the "Florence on the Elbe",

Andreas Hermann Chair of the Meeting Kevin Peikert Congress Secretary We tried hard to reduce costs wherever possible. We want to encourage young scientists to attend the meeting. Registration fee includes the meeting costs and food & beverage during the day.

**Registration fee**: 100 € [full meeting]/50 € [day ticket] **Discounted registration fee**\*: 50€ [full meeting] \*discounts are available for students/PhD students.

Registration Link:

Www.ukdd.de/neuroacanthocytosis-syndromes-meeting

Accommodation in the meeting's hotel is not included. For reservation of your hotel room please use the official reservation form provided by the hotel. A block of hotel rooms for your reservation is available until February 9, 2018.

Accommodation and registration for patients and caregivers will not be charged. However, they are kindly ask to register on the website.

Deadline for Abstracts: February 1st, 2018

# CONTACT US

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Meeting's Website:

www.ukdd.de/neuroacanthocytosis-syndromes-meeting

# MEETING VENUE

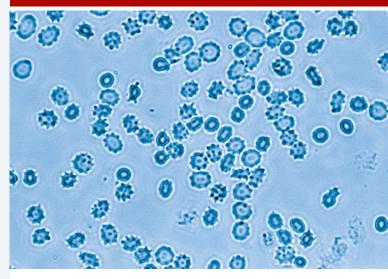
The meeting will be held at: Radisson Blu Park Hotel & Conference Centre, Dresden Radebeul Nizzastrasse 55, D-01445 Dresden Radebeul, Germany

#### https://www.radissonblu.com/en/parkhotel-dresdenradebeul

The conference hotel is located just a few kilometers from Radebeul city center, it also provides proximity to Dresden. For arrival information, e.g. from Dresden international airport or main station, please visit the hotel's website.

# 9<sup>th</sup> International Meeting on Neuroacanthocytosis Syndromes

March 23-25, 2018, Dresden, Germany



MAIN SPONSORS:







## PRELIMINARY AGENDA

### THURSDAY, MARCH 22, 2018:

Optional: Arriving of patients and caregivers

### FRIDAY, MARCH 23, 2018:

Patients and Caregivers Session I		
11:00-13:00	Registration / Lunch	
13.00-13:15	Introduction by Ginger and Alex Irvine and	
	Joy and Mark Williford	
13:15-13.30	Roundtable introduction of all participants	
13:30-14:00	Short clinical overview (Walker, Danek)	
14:00-15:00	New developments in translational research	
	(Danek, Hermann)	
15.00 15.20	Coffee break	

15:00–15:30 Coffee break

15:30–16:30 Medical Q & A (Walker, Danek, Hermann)

#### Scientists/Patients and Caregivers

13:00-17:00	Registration
17:00	Conference Opening
17:30-19:00	Scientific Opening Session
19:00	Reception
19:30	Dinner

### SATURDAY, MARCH 24, 2018:

Scientists/Patients and Caregivers		
09:00-12:00	Scientific talks	
12:00-13:00	Lunch	
13:00-15:00	Parallel sessions I: Scientific talks	
	Patients and Caregivers Session II:	
	Physical therapy/logo therapy/music therapy	
15:00–15:30	Coffee break	
15:30-17:00	Parallel sessions II: Scientific talks	
	Patients and Caregivers Session III:	
	Caregiver issues	
18:00-19:00	Poster Session	
19:30	Dinner	

End of Patient and Caregiver meeting

### SUNDAY, MARCH 25, 2018:

#### Scientists

- 08:30–10:00 Scientific workshop: Results and questions from two experimental treatment approaches
- 10:00–10:30 Coffee break
- 10:30–13:00 Scientific meeting: Workshop on future directions of scientific work
- 13:00-14:00 Lunch and End of meeting

Detailed agenda is going to be published soon, please check the meeting's website.



- Sami Barmada, Neurology, Medical School, University of Michigan, USA
- Cathy Collins, Molecular, Cellular & Developmental Biology, University of Michigan, USA
- Adrian Danek, Neurologische Klinik, Klinikum der Universität, LMU Munich, Germany
- **Ricardo Escalante**, Instituto de Investigaciones Biomédicas Alberto Sols, Madrid, Spain
- Lucia De Franceschi, Department of Medicine, University of Verona, and Azienda Ospedaliera Universitaria di Verona (AOUI-Verona), Italy
- **Bob Fuller**, Cellular and Molecular Biology Program, Medical School, University of Michigan, USA
- Florian Lang, Department of Physiology, Eberhard-Karls-Universität Tübingen, Germany
- Masayuki Nakamura, Kagoshima University Graduate School of Medical and Dental Sciences, Department of Psychiatry, Kagoshima, Japan
- Aaron Neiman, Department of Biochemistry and Cell Biology, Stony Brook University
- Ody Sibon, Department of Cell Biology, University Medical Center Groningen, University of Groningen, The Netherlands
- Ruth H. Walker, Department of Neurology, James J. Peters Veterans Affairs Medical Center, Bronx, NY, and Mount Sinai School of Medicine, New York, NY, USA
- Teresa Zoladek, Institute of Biochemistry and Biophysics, Polish Academy of Sciences, Department of Genetics, Warsaw, Poland

# TOPICS

I. Introduction Neuroacanthocytosis Syndromes

II. Basic Science Topics Lower organisms model systems Yeast Dictyostelium Animal models

Drosophila VPS13A mouse
 Cell models
 iPSC

# Disease pathways

Lyn pathway PI3K pathway

III. Clinical translation and standard of care Standard of Care in ChAc Patient centered care Clinical translation Clinical trial readiness Dasatinib Lithium

IV. Poster Session V. Patients' Program

