



INTERNATIONAL SYMPOSIUM

NEUROACANTHOCYTOSIS
COHEN SYNDROME
OTHER **VPS13**-RELATED DISORDERS

2025

NA PATIENT-ORIENTED PROGRAMME

Friday 12 September - Sunday 14 September

Jules-Gonin Eye Hospital, Fondation Asile des Aveugles

Avenue de France 15, CH-1004 Lausanne, Switzerland

SCIENTIFIC PRESENTATIONS
The Auditorium

PATIENT RELATED SESSIONS
**Room Louis Braille 1, Room Louis Braille 2,
Room Elisabeth de Gejat**

LAST UPDATED: 2 SEPTEMBER 2025

FRIDAY 12 SEPTEMBER

SPEAKERS

PARALLEL PATIENT SESSIONS: NEUROACANTHOCYTOSIS SYNDROMES

Chair: Ginger Irvine

11:00 - 13:00 REIKI SESSIONS (4 X 20 MINS)

Led by: Sally Cowan

13:00 - 14:30 LUNCH BREAK

14:30 - 15:50 HOW CAN OCCUPATIONAL THERAPY HELP NA PATIENTS

Led by: Joana Valente

(to join remotely, please email info@naadvocacy.org and we'll send you the personalised MSTeams invitation)

15:30 - 16:00 GROUP PHOTO / COFFEE BREAK

16:00 - 17:30 REIKI SESSIONS (3 X 20 MINS)

Led by: Sally Cowan

17:00 - 18:00 POSTER VIEWING SESSION / COFFEE BREAK

Selected topics on VPS13-related studies, including cell and animal models

FROM 19:00 NETWORKING DINNER

Location: Aquatis Hotel Restaurant, Rte de Berne 148, 1010 Lausanne

Sponsored by Cohen Syndrome Research Foundation



ABOUT REIKI

Reiki is a Japanese form of energy healing based on the concept of Ki – the universal life force that flows through all living things. It's a gentle, non-intrusive technique that channels the Reiki energy to balance the chakras (energy points), promote deep relaxation and instill a sense of well-being.



JOANA VALENTE

Occupational Therapist, Luxembourg

Joana is an occupational therapist working for the Luxembourg Red Cross in home-based care. Her practice focuses on older adults and individuals living with Parkinson's disease and other neurodegenerative conditions.

Joana is currently completing a Master's in Gerontology at the University of Luxembourg and she holds a Bachelor's degree in Occupational Therapy from Brussels.

As a trainer-in-training for ParkinsonNet Luxembourg, she is actively involved in promoting interdisciplinary collaboration and delivering practical strategies to support autonomy, upper limb function, and daily life participation. She is passionate about empowering both patients and caregivers through tailored interventions and education.



SALLY COWAN

Reiki Practitioner

Having lived in Japan in the 1990s, Sally is passionate about conscious ways of living, mindfulness practices and holistic health. She felt called to learn Reiki during the Covid pandemic as part of her own healing journey and qualified in Usui Reiki Levels 1 and 2 with the Reiki Maya London Centre in 2022.

SATURDAY 13 SEPTEMBER

SPEAKERS

PARALLEL PATIENT SESSION: NEUROACANTHOCYTOSIS SYNDROMES

Chair: Joy Willard-Williford

11:00 - 12:00

MENTAL HEALTH RESOURCES FOR THOSE AFFECTED BY NA SYNDROMES

Led by: Matt Bolz-Johnson

(to join remotely, please email info@naadvocacy.org and we'll send you the personalised MSTeams invitation)

12:30 - 14:00

LUNCH BREAK

14:00 - 15:30

"IF I GET TO KOREA, I'LL TELL YOU"

Actor: José Miguel Abrantes Figueiredo

This is a theatre play performance in Portuguese - an English written translation will be provided for the audience.

The play was written by José Miguel, who is also delivering the monologue play. He is a VPS13A diagnosed patient. It is intended for a small audience and it lasts approximately 20 mins, so there may be two successive, identical performances.

15:30 - 16:00

COFFEE BREAK

16:00 - 17:30

HOW TO KEEP THE JOY OF COMMUNICATION AND EATING AND DRINKING

Led by: Dr Elina Tripoliti

(to join remotely, please email info@naadvocacy.org and we'll send you the personalised MSTeams invitation)

17:00 - 18:00

POSTER PRESENTATIONS / VIEWING

Selected topics on VPS13-related studies, including cell and animal models



MATT BOLZ-JOHNSON

Mental Health Lead & Healthcare Advisor / Healthcare and Research Director, EURORDIS – Rare Diseases Europe

Matt has worked at EURORDIS since 2014 as a patient advocate. Matt has over 15 years experience working in the rare diseases field specialising in the selection and approval of expert centres in the NHS, England and for the European Reference Networks used by the European Commission. He also has supported the development of clinical networks for rare diseases at a national, regional and international level, ensuring patient groups to be active and be leaders in these networks.

Matt is leading the development of EURORDIS Mental Health Programme and Mental Health Partnership Network and coordinating advocacy actions as well as leading the development of a Mental Health Toolkit for Rare Conditions.

Matt is also an active advocacy lead for ATMPs working on EURORDIS Rare Impact initiative, Join4ATMP & ERDERA ATMP research, to streamline the ATMP development pathway and propose actionable solutions to improve patient access to cell and gene therapies in Europe.

Previously, Matt worked in NHS, England as a hospital manager and commissioner and specialised in rare disease and highly specialised healthcare.



DR ELINA TRIPOLITI

Clinical Specialist Speech and Language Therapist

Elina is a Clinical Specialist Speech and Language Therapist working at the National Hospital for Neurology and Neurosurgery, Queen Square, and an Honorary Senior Lecturer at the Department of Clinical and Movement Neurosciences, Institute of Neurology, UCL.

She is responsible for treating communication and swallowing problems in patients with Movement Disorders, mainly PD, PSP, MSA and Dystonia. She provides intensive therapies such as the Lee Silverman Voice Treatment (www.lsvtglobal.com) and the Expiratory Muscle Strength Training (emst150.com) and she has been a pioneer in delivering therapy through the internet. She founded the Movement Disorders Speech Lab for the investigation of acoustical, perceptual and aerodynamic aspects of speech.

She has a degree in Clinical Psychology from the University of Athens and a postgraduate degree in Speech & Language Therapy from City University, London. She was awarded her PhD in Neurological studies from UCL Institute of Neurology in 2010 (with Professor Limousin and Prof Hariz as mentors and supervisors) investigating the speech changes after Deep Brain Stimulation for patients with PD and Dystonia.

She is a founding member and a Trustee of the Sing for Joy Choir (singforjoychoirs.org.uk), and a firm advocate of the role of music, singing and dancing in speech rehabilitation.

"In the truest sense, Elina makes sure patients are heard" (www.parkylife.com/dr-elina-tripoliti)



ADVOCACY FOR
NEUROACANTHOCYTOSIS
PATIENTS

www.naadvocacy.org
info@naadvocacy.org



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**A world where neuroacanthocytosis
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