

The Danish CHARGE network and The National Board of Social Services
proudly invite you to participate in

CHARGE Conference 2014

About the conference

The conference will give the participants an update based on the latest research and experience on essential medical issues concerning CHARGE syndrome such as immunological and adrenal function, puberty and growth issues, heart malformation and treatment, meal time challenges, neuropaediatric aspects and will furthermore discuss the possible benefits of a multi disciplinary clinic for patients, their families and professionals.

Who can attend?

We invite all relatives and professionals (medical specialists, educators, social workers, administrators, consultants, researchers, therapists etc) with an interest in CHARGE syndrome to attend the conference. An understanding of the issues discussed at this conference is important for everybody with CHARGE syndrome and the persons around them.
The conference language is English.

Program

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| 09.00 - 10.00 | Registration and morning buffet |
| 10.00 - 10.05 | Opening and welcome
By Lisbeth Tranebjærg, the program committee |
| 10.05 - 11.00 | Experiences with multidisciplinary clinical follow-up of 90 patients with CHARGE syndrome
By Conny van Ravenswaaij-Arts, University of Groningen/NL |
| 11.00 - 11.20 | Immunological and adrenal function in CHARGE syndrome
By Monica Wong, University of Groningen/NL |
| 11.20 - 11.35 | Coffee/tea break |
| 11.35 - 11.55 | CHARGE – a mixed immunological condition?
By Kristian Assing, Odense University Hospital/DK |
| 11.55 - 12.15 | Heart malformations in CHARGE syndrome. A systematic study in molecularly confirmed patients. Research by Nicole Corsten-Janssen, University Medical Center Groningen/NL
Presented by Conny van Ravenswaaij-Arts, University of Groningen/NL |
| 12.15 - 13.15 | Lunch |
| 13.15 - 14.00 | Endocrinological aspects of CHARGE syndrome: Puberty and growth
By Jeremy Kirk, Birmingham Children's Hospital/UK |
| 14.00 - 14.30 | Challenges of meal times for children with CHARGE syndrome
By Steve Rose, Sense/UK |
| 14.30 - 15.00 | Parents' perspective: Our dialogue with Albert - A book in writing
By Thomas Aue Sobol, parent/DK |
| 15.00 - 15.30 | Coffee/tea break |
| 15.30 - 16.00 | Neuropaediatric aspects of CHARGE syndrome: The Danish experiences
By Hanne Hove, Dept. Clinical Genetics, Rigshospitalet/DK and Stense Farholt, Skejby/Aarhus University Hospital/DK |
| 16.00 - 16.45 | Questions, discussion: How to secure FULL care for patients with CHARGE syndrome and their families? Panel consisting of the speakers will participate.
By Inge Mogensen, the program committee |
| 16.45 | Thank you and goodbye |
| 17.00 - 18.00 | Meeting for parents. Arranged and hosted by the Danish CHARGE Network. |

Practical information

Time

The conference will take place on Thursday March 20, 2014 at 10:00 – 16:45.

Venue

Scandic Copenhagen, Vester Soegade 6, 1601 Copenhagen V, Denmark, scandichotels.com/copenhagen

Language

The conference language will be spoken English. If you bring your own interpreters we kindly ask you to let us know in order to make practical arrangements.

Price

DKK 1000 per person. Included in the price is morning buffet from 09:00, lunch, coffee/tea, fruit during the day.

Registration

Please register at www.socialstyrelsen.dk no later than March 1, 2014. The registration is available at <http://www.socialstyrelsen.dk/handicap/dovblindfodt/aktiviteter/charge-konference>.

In order to cancel your registration please contact konferencer@sm.dk no later than March 1, 2014. Refund of the participation fee of DKK 1000 is not possible after this day.

Accommodation

Accommodation will be possible at the conference venue as well as many other places in Copenhagen. If you need help do not hesitate to contact us.

Arranged by

The conference is arranged by the Danish CHARGE network – a network of parents and professionals around persons with CHARGE syndrome – in collaboration with SOCIALSTYRELSEN/The National Board of Social Services.

Contact

Please do not hesitate to contact us if any questions about the conference: Jytte Olsen, SOCIALSTYRELSEN/ The National Board of Social Services, jos@socialstyrelsen.dk, +45 4193 2463