

Emskirchen, January 2016

Invitation to the 2nd German Professional Day on the CHARGE syndrome

Dear Professionals interested in the CHARGE syndrome,

You are cordially invited to attend the

2nd German Professional Day on the CHARGE syndrome

from the 16th to the 17th of June, 2016 at Oberwesel.

We are delighted to announce that the CHARGE experts Dr. David Brown (USA), Dr. Gail Deuce (GB) and Rob Last (Australia) will be presenting interesting and informative lectures.

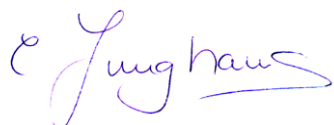
Attached you will find the program of the Professional day with detailed information as well as the registration form.

The topics to be addressed at the symposium are aimed at professionals who treat and deal with CHARGE-affected individuals. Please note that the meeting will not be discussing family-related issues.

However, should you also wish to participate in the following German CHARGE-conference which is going to take place from the 17th to 19th of June, 2016, do let us know in advance.

We are looking forward to seeing you at Oberwesel!

Yours sincerely,



Claudia Junghans

1st President

Program

Thursday, 16th, June 2016:

from 12.00 o'clock	Arrival and lunch (snack)
2.00 p.m.	<u>Claudia Junghans, President (Germany)</u> Official welcome and information
2.30 p.m.	<u>Lecture by Rob Last (Australia)</u> <i>"Quality not quantity – Thoughts on communication, behavior, play and passions"</i>
4.00 p.m.	Coffee break
4.30 p.m.	<u>Lecture by Dr. David Brown (USA)</u> <i>"Posture and movement in CHARGE syndrome"</i>
From 6.00 p.m.	Dinner and get together
7.30 p.m.	<u>Ulla Füsler interviewing her son Florian Drewes (Germany)</u> <i>„My life with CHARGE syndrome“</i> Everyday life and development of Florian Drewes

Friday, 17th, June 2016:

from 7.30 a.m.	Breakfast
9.00 a.m.	<u>Lecture by Dr. David Brown and Julie Maier (USA)</u> <i>„Looking at the world through rose-colored glasses“</i> Approaches to positive assessment
10.45 a.m.	<u>Lecture by Dr. Gail Deuce, Sense (UK)</u> <i>„Potential learning characteristic and teaching strategies“</i>
12.00 o'clock	Official end of the Professional day, lunch and departure
<i>from 1.30 p.m.</i>	<i>Start of the 10th German CHARGE conference</i> <i>We recommend to visit these lectures, too.</i>
2.00 p.m.	<u>Lecture by Nancy Salem-Hartshorne, Ph.D. (USA)</u> <i>Behaviors and OCD "Why does my child do that?"</i>
3.45 p.m.	Break
4.15 p.m.	<u>Lecture by Prof. Dr. Tim Hartshorne (USA)</u> <i>"Anticipation and behavior"</i>

For a communication without **barriers sign language interpreters** will be on hand (German sign language).



Organizational Information 2nd German Professional Day

All presentations in English will be simultaneously translated. For a communication without barriers sign language interpreters will be on hand (German sign language).

Additional information:

- *CHARGE Welcome Desk with information on the CHARGE syndrome and on our German Self-Supporting Group*
- *Book exhibition*
- *Poster exhibition*

Venue:

Rheintal-Jugendherberge
Auf dem Schönberg
D - 55430 Oberwesel

Rooms:

There will be the possibility for the overnight stay in the youth hostel Oberwesel. Please note that single rooms are limited. Therefore please let us know if a room can be shared. Please bring your own towels, bed linen will be provided.

Meals (beverages not included):

Thursday, June 16 th , 2016:	Lunch (Snack) Coffee break Dinner
Friday, June 17 th , 2016:	Breakfast Lunch

Participation fees:

Each participant:	90,- € without room (incl. participation fee and dinner on Thursday or lunch on Friday – beverages <u>not</u> included)
	115,- € including room (incl. participation fee, full board – beverages <u>not</u> included, room).

Payment:

After receipt of your registration we will send you a reservation confirmation and an invoice.
Please pay on receipt of this invoice, using the invoice number!

Cancellation:

A cancellation free of charge is only possible up to 4 weeks before your journey. Subsequently, the costs can only be refunded if the room can be re-booked. We are unable to refund any costs incurred by an untimely arrival or departure, or for arrivals with fewer people than booked.

Contact Organization:

Mrs. Claudia Junghans
CHARGE Syndrom e.V.
Borbath 29
D – 91448 Emskirchen
info@charge-syndrom.de
Tel: 0049 (0) 9104 / 826 345
Fax: 0049 (0) 9104 / 826 345

CHARGE Syndrom e.V. - Elternkreis betroffener Kinder
Borbath 29, D-91448 Emskirchen
info@charge-syndrom.de
www.charge-syndrom.de



Binding Registration

2nd Professional Day on the CHARGE-Syndrome - June 16th to June 17th at Oberwesel

Please return no later than **March 31st, 2016**

Participant:

Name/ first name: _____

Institution: _____

Address: _____

Phone: _____

Email: _____

Additional information:

I am a deaf professional / student and require a sign language translation for the lectures.
(It may be necessary for you to apply to your IFD to cover the costs of an interpreter. Should this be the case, you will receive an appropriate letter together with your confirmation of registration, which you may then submit to the IFD).

Others: _____

Participation:

Participation only on _____ (I don't need a room).

I need a room

single room (June 16th to June 17th, 2016)

I will share a room with _____

I would also like to attend the Family Conference (**only on Friday afternoon**)

I would like to attend the whole Family Conference – (**Including overnight stay-**
please fill out the intended registration form)

I'm going to bring a poster for the poster exhibition

I will take part in the following meals:

Lunch (snack) on Thursday

Dinner on Thursday

Lunch on Friday

Vegetarian food

Allergies _____

Date/ signature: _____

About the lecturers:



Dr. David Brown, Educational Specialist

David entered the specialist area of deaf-blindness in 1983 and has become a leading and well-published practitioner in the field particularly with reference to CHARGE syndrome. In his roles as Head of the Family Education and Advisory Service of SENSE (the National Deafblind Association) in the UK (1983- 2000), and as Educational Specialist for California Deaf-Blind Services (since August 2000), he has worked with over 150 children and young people with CHARGE. For 25 years David has been writing training manuals for universities and other training organizations, and publishing articles on a variety of topics in journals and magazines such as "Talking Sense", "Deafblind Education", "Eye Contact", "Special Children", "Deaf-Blind Perspectives", "reSources", "Deafblind International Review", "The American Journal of Medical Genetics", and "Child: Care, Health and Development". His writings have been translated into French, Italian, Spanish, Portuguese, Danish, Norwegian, Swedish, Finnish, German, Greek, Japanese, and Russian. David has contributed to staff training courses in 14 countries, and he has presented at CHARGE Syndrome Conferences in England, the USA, Australia, New Zealand, France, Norway, Sweden, Denmark, Switzerland, and Germany. David has also worked as a consultant with the state deaf-blind projects in 18 states of the USA. David has a credential in the Education of Students with Multi Sensory Impairments from the University of Birmingham, an Honorary Doctorate of Science from Central Michigan University for his research work with children with deaf-blindness, and in 2013 was awarded the Deafblind International 'Lifetime Achievement Award' for "innovative and visionary work with people with deafblindness".



Gail Deuce, PhD has approximately 30 years experience in the field of special education, working initially in schools for children with severe learning difficulties and then a school for the deaf before moving into peripatetic work focusing on learners who are deafblind. Gail currently works as a specialist MSI (deafblind) outreach teacher for a school in a London borough and is also a freelance consultant, in addition to becoming an Associate for Sense. Gail is also a tutor for the University of Birmingham on the education of learners who are MSI. Gail has a particular interest in CHARGE syndrome and is on the committee for the CHARGE Family Support Group in the UK. She has recently successfully completed her PhD, exploring the education of learners with CHARGE.



Prof. Dr. Tim Hartshorne, PhD is a professor of psychology, specialized in school psychology, at Central Michigan University. He is the grant holder for DeafBlind Central: Michigan's Training and Resource Project, which provides support to children who are deafblind in Michigan. He has been researching and presenting about CHARGE syndrome since 1993, motivated by the birth of his son with CHARGE in 1989. He has been awarded the Star in CHARGE by the CHARGE Syndrome Foundation. He is first editor of the book *CHARGE Syndrome*.



Rob Last is a special education teacher who has a long history working with children who have sensory disabilities, particularly in hearing and vision. Since the mid 1980's he has been involved with children who have CHARGE syndrome and their families. He and a group of parents established the CHARGE Syndrome Association for Australia and New Zealand in the late 1980's. Rob has been a presenter at many of the CHARGE Syndrome International

Conferences since the first in St Louis in 1993 and the first CHARGE Syndrome Conference in Australia and New Zealand held in Sydney 1994. He presented at the CHARGE Syndrome Conference in Germany in 2012. Rob's career has been as an Early Childhood Educator with the Royal Institute for Deaf and Blind Children in Sydney and the Royal Victorian Institute for the Blind and Vision Australia in Melbourne, Australia. He continues his work with the CHARGE Syndrome Association of Australia and New Zealand as a Director for the state of Victoria and as Director of Outreach for Australia and New Zealand. Rob has the pleasure of meeting and being in contact with families from all over Australia and New Zealand as well as the CHARGE international community.



Nancy Salem-Hartshorne Ph.D. is an Assistant Professor of Psychology at Delta College in Bay City Michigan and a School Psychologist. She has authored articles and book chapters about developmental outcomes for individuals with CHARGE syndrome. Her young adult son Jacob has CHARGE syndrome and lives in his own home. Nancy has been involved with language and education of children with CHARGE for 20years. She advocates for individuals with disabilities, teamwork, thorough planning, and forward thinking for quality life outcomes for all individuals.

Dr. Jeremy Kirk is a Consultant Pediatric Endocrinologist (Honorary Reader) at the Diana Princess of Wales Children's Hospital in Birmingham, UK. Jeremy has a special interest in hormonal and growth problems in CHARGE syndrome.



Prof. Conny van Ravenswaaij, MD, PhD (Consultant) is a clinical geneticist with a long-lasting experience in genetic and clinical studies on CHARGE syndrome. Since her group discovered CHD7, the gene responsible for CHARGE syndrome, in 2004, she coordinates a multidisciplinary clinic and supervised several PhD research projects dedicated to the syndrome. Her research is mostly based on questions raised by the parents and often results in clinical guidelines. Thus far she has published over 25 papers and four book chapters on CHARGE syndrome



Julie Maier (consultant) is an Educational Specialist for CDBS. She provides technical assistance to students with deaf-blindness, families, and school teams. Julie also is a faculty member in the SFSU Department of Special Education and has served as a research assistant, guest lecturer, course instructor and fieldwork supervisor in the Moderate-Severe teaching credential and Masters degree programs since 1999. Julie has been involved in the field of special education since 1987 when she first met and taught individuals with deaf-blindness in community-based adult program and later in inclusive schools in Berkeley.



Claudia Junghans, President of the German CHARGE Family Support Group and mother of an 11 year old son with CHARGE syndrome. She regularly lectures on the CHARGE syndrome from the point of view of an affected mother. She also heads the office of the German CHARGE Family support group.



Dr. Julia Benstz, Vice president of the German CHARGE Family Support Group and mother of a 14 year old daughter with CHARGE syndrome. She currently works as a hospital doctor in neurology.



Frau Ulla Fűßer, member of the German CHARGE group and mother of a 25 years old son with CHARGE syndrome. She is working with joy and passion for almost 20 years in different fields of social work. Her focus are people with hearing impairments and young people with special needs and also people with CHARGE syndrome. She just finished her education as a presenter and coach for PCP (Person Centered Planning)

Lecture by Rob Last (Australia)

“Quality not quantity – thoughts on communication, behavior, play and passions”

The presentation will focus on early communication and behaviour, address the importance of establishing a meaningful communication system for children with CHARGE and the strategies that may be available for this. Play strategies will be demonstrated through video, photos and discussion. Passions/obsessions as educational opportunities will be discussed and illustrated through video and photos. We will discuss the importance of appropriate early intervention strategies to ensure positive outcomes. Case studies and photos will support this discussion. ‘Meltdowns’ will be discussed as a form of communication, why these may occur and strategies for managing these. Communication systems will be highlighted as well as the supports available in the acquisition these.

Lecture by Dr. David Brown (USA)

“Posture and movement in CHARGE syndrome”

The complex multiple anomalies involved in CHARGE syndrome present huge barriers to development. Children with this syndrome are forced to experiment and explore alternative ways of achieving what they want because the conventional, so-called ‘normal’, ways are not available to them. This is seen most clearly in the ways that they physically manage their bodies in space, to maintain postural security while also developing independent mobility. Observing and analyzing these behaviors from a multi-sensory perspective helps us to understand the way that their impaired sensory systems are working, and so gives us useful pointers to the best ways to work with them. This perspective can also help us to identify the ways in which the children use postures to self regulate. The presentation will feature many photographs demonstrating these unusual, apparently weird, but actually highly functional postural behaviors.

Lecture by Dr. David Brown and Julie Maier (USA)

***„Looking at the world through rose-colored glasses“
Approaches to positive assessment***

This presentation is based upon two articles that Julie and David wrote for the CDBS newsletter in 2014. We will examine and discuss the perspectives and assumptions educators, medical professionals, and other related service providers often employ when viewing students with CHARGE Syndrome. These perspectives and assumptions then influence the direction taken during assessment and planning development of educational goals and programs for individuals with CHARGE Syndrome. We will share a more effective, child-centered approach.

Lecture by Dr. Gail Deuce, Sense (UK)

„Potential learning characteristic and teaching strategies”

“The education of learners with CHARGE syndrome” - CHARGE syndrome is now considered to be the major genetic cause of congenital deafblindness. There has been some discussion as to whether learners with CHARGE are distinct from the wider deafblind population and Gail has recently completed her PhD studies exploring this issue and the education of learners with CHARGE.

Lecture by Nancy Salem-Hartshorne, Ph.D. (USA)
Behaviors and OCD *“Why does my child do that?”*

All of us have repetitive or compulsive behaviors. All of us have hobbies. But when we see these obsessions and compulsions in our children with CHARGE, they can look odd or disturbing, or may prevent them from accomplishing all that they can, and we worry. Anxiety is the key! Dr. Hartshorne will talk about strategies to address anxiety and OCD-like behaviors in children with CHARGE syndrome.

Lecture by Prof. Dr. Tim Hartshorne (USA)
“Anticipation and Behavior”

Anxiety about what is occurring or going to happen is one source of challenging behavior for children with CHARGE. This presentation reviews calendar systems and activity routines as ways to increase the predictability of life for those who have CHARGE, and to reduce the experience of anxiety and the incidence of challenging behavior.