



Emskirchen, January 2016

**Invitation to the anniversary CHARGE conference from 17<sup>th</sup> – 19<sup>th</sup> June, 2016  
in Oberwesel**

Dear CHARGE-families,

Coming events cast their shadows!

We are delighted to send you attached our program for the 10<sup>th</sup> CHARGE conference marking the 10 year anniversary of the CHARGE Syndrome e. V.!

With Dr. David Brown, Prof. Dr. Tim Hartshorne, Nancy Salem-Hartshorne, Dr. Jeremy Kirk, Rob Last, Prof. Dr. Conny van Ravenswaaij and Dr. Gail Deuce international CHARGE experts have confirmed their attendance, which in recent years have become a lot more for us than interesting speakers, they became friends. Therefore we are looking forward to hearing interesting lectures and meeting with this year's speakers.

The frame program offers especially a lot of fun for the children during the lecture periods. Of course, we want to offer the adult time and space to come together this week-end and celebrate the CHARGE Syndrome e.V..

We are proud that we have the TV presenters Ralph Caspers and Shary Reeves (known from "Wissen macht Ah!") as patrons for our conference. On Saturday, we also expect special surprise guests ...

Please send us your application with the enclosed registration form

**by 31<sup>st</sup> March 2016.**

We look forward to seeing you and your family in Oberwesel!

For all further inquiries, we are of course always happy to help you.

Best regards,

Claudia Junghans  
(1<sup>st</sup> president)

## Binding Registration - 10<sup>th</sup> German CHARGE Conference 17<sup>th</sup> - 19<sup>th</sup> June, 2016

Please fill out this registration form and return it by no later than **March 31<sup>st</sup>, 2016**.

We would like to register the following persons:

| Name | First name | Please tick  | Age of the child |
|------|------------|--|------------------|
|      |            | <input type="checkbox"/> adult <input type="checkbox"/> child <input type="checkbox"/> child with CHARGE |                  |
|      |            | <input type="checkbox"/> adult <input type="checkbox"/> child <input type="checkbox"/> child with CHARGE |                  |
|      |            | <input type="checkbox"/> adult <input type="checkbox"/> child <input type="checkbox"/> child with CHARGE |                  |
|      |            | <input type="checkbox"/> adult <input type="checkbox"/> child <input type="checkbox"/> child with CHARGE |                  |
|      |            | <input type="checkbox"/> adult <input type="checkbox"/> child <input type="checkbox"/> child with CHARGE |                  |
|      |            | <input type="checkbox"/> adult <input type="checkbox"/> child <input type="checkbox"/> child with CHARGE |                  |

We need rooms for \_\_\_\_\_ **adults** and \_\_\_\_\_ **children**    baby bed (only limited number available)  
 from \_\_\_\_\_, June 2016 until \_\_\_\_\_, June 2016 = \_\_\_\_\_ nights

### Arrival:

- Thursday, 16<sup>th</sup> June, 2016, approximately** \_\_\_\_\_ o'clock  
 (the number of rooms is limited, for additional costs please see back page)
- Friday, 17<sup>th</sup> June, 2016** approx. \_\_\_\_\_ o'clock    **Saturday, 18<sup>th</sup> June, 2016** approx. \_\_\_\_\_ o'clock
- Participation only on **Saturday, 18<sup>th</sup> June, 2016** with \_\_\_\_\_ adults and \_\_\_\_\_ children

### We would like to:

- attend the grandparents' seminar on Saturday, 18<sup>th</sup> June 2016 with \_\_\_\_\_ persons
- have a counseling interview on genetics with **Prof. Conny van Ravenswaaij**

### We take part in the following meals:

- Lunch on Friday                       Dinner on Friday                       Lunch on Saturday
- Dinner on Saturday                       Lunch on Sunday
- Departure on Sunday, before lunch. Please provide packed lunch for \_\_\_\_\_ persons.
- Vegetarian food for \_\_\_\_\_ persons
- Allergies: \_\_\_\_\_ Name: \_\_\_\_\_

### Program for children and teenagers:

- Participation on the youth program
- Participation on the soccer competitions with \_\_\_\_\_ children. Age: \_\_\_\_\_
- Participation on the "High wire" course for children and teenager (from 6 years) with \_\_\_\_\_ children
- I agree that my children participate in swimming lessons (from 6 years)
- Swimmer** - number of children \_\_\_\_\_ Age: \_\_\_\_\_
- Non-swimmer** - number of children \_\_\_\_\_ Age: \_\_\_\_\_
- Signature of parent or guardian: \_\_\_\_\_

Any person with CHARGE syndrome receives a jubilee T-Shirt! Please specify size \_\_\_\_\_

### Additional Information:

- I'm a professional                       I'm a student
- 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).

### Personal data:

Surname, First name: \_\_\_\_\_

Institution: \_\_\_\_\_

Street: \_\_\_\_\_

City: \_\_\_\_\_ Country: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_

# INFORMATION ON THE GERMAN CHARGE CONFERENCE 2016

## VENUE

Rheintal-Jugendherberge - Familien- und Gästehaus  
Auf dem Schönberg  
D - 55430 Oberwesel

## PRICES

### Participation fees:

- 60,00 €** = per adult (**members and students**) for the whole weekend incl. participation fees, overnight stay and full board (Friday - Sunday) - Beverages not included.
- 120,00 €** = per adult (**non-members and professionals**) for the whole weekend incl. participation fees, overnight stay and full board (Friday - Sunday) - Beverages not included.
- Free of charge= all persons with CHARGE syndrome**
- Free of charge= all siblings until the age of 17,99 years**
- plus 40,00 €** = **only for arrivals on Thursday, 16.06.2016** per adult for **one** overnight stay with including dinner on Thursday and breakfast on Friday - Beverages not included.

### Participation only on Saturday:

- 55,00 €** = per adult (member) participation only on Saturday
- 55,00 €** = per student participation only on Saturday
- 110,00 €** = per adult (non-member) participation only on Saturday

It is possible for participants without membership to join the CHARGE Syndrom e.V. (annual fee of 30 €) before the conference starts and thus benefit from the special membership rates outlined above. You can also fill out a membership application at the conference and then get the extra charge refunded. In reasonable cases a reduction of the participation fees may be requested.

## 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.

## SPECIFIC FEATURES

- On Saturday evening we invite all families to a **festive Italian Buffet** (Beverages not included).
- For our children with CHARGE who are tube-fed or have swallowing difficulties, a microwave, a fridge, a kettle, and a food blender will be available.
- For reasons of hygiene you are not permitted to bring your own food and drink. Exceptions: baby food, formula food and blended menus for children with CHARGE.
- Dogs are not permitted in the youth hostel.
- Please bring your own towels.

## PLEASE NOTE!

The deadline for confirmed room reservations is **March 31<sup>st</sup>, 2016**.

After this a reservation is only possible on request. Please also note that the number of rooms is limited and families with affected children will be given preferential treatment.

### Please send back to:

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

## Program

### Friday, 17<sup>th</sup>, June 2016:

from 12.00 o'clock

#### Arrival and lunch

Start of individual meetings with the CHARGE experts

1.30 p.m.

#### Claudia Junghans, President (Germany)

Official welcome and information

#### Opening speech

#### Prof. Conny van Ravenswaaij (NL)

“The Passion in CHARGE Syndrome”

2.00 p.m.

#### Lecture by Nancy Salem-Hartshorne, Ph.D. (USA)

Behaviors and OCD “*Why does my child do that?*”

3.45 p.m.

Break

4.15 p.m.

#### Lecture by Prof. Dr. Tim Hartshorne (USA)

“*Anticipation and Behavior*”

From 6.00 p.m.

Dinner

7.30 p.m.

Family introductory session, campfire bread (bannocks) and get together

### Saturday, 18<sup>th</sup>, June 2016:

from 7.30 a.m.

Breakfast

10.00 a.m.

#### Claudia Junghans, President (Germany)

**We celebrate 10 Years of CHARGE Syndrom e.V.**

Review and milestones

**Ralph Caspers and Shary Reeves – the patrons of the conference** transfer their greetings

11.00 a.m.

#### CHARGE Adult Panel

„My life, my wishes, my aims“

12.00 o'clock

Lunch

2.00 p.m.

#### Lecture by Dr. David Brown (USA)

“*Posture and movement in CHARGE syndrome*”

- 3.30 p.m. **Coffee break**
- 4.00 p.m. **Lecture by Dr. Jeremy Kirk, (UK)**  
*“All you ever want to know about sex hormones, preparing for puberty and sexuality”*
- 6.00 p.m. **Festive Italian Buffet**
- 7.30 p.m. **Live music with „Max und der Plancke Wahnsinn“**

### Sunday, 19<sup>th</sup>, June 2016:

- from 7.30 a.m. **Breakfast**
- 9.30 a.m. **Lecture by Rob Last, (Australia)**  
*“Quality not quantity – thoughts on communication, behavior, play and passions”*
- 10.30 a.m. **Lecture by Dr. Gail Deuce, (UK)**  
*„Development of friendships in school”*
- 12.00 o'clock **Lunch**
- 1.30 p.m. **Lecture by Prof. Dr. Tim Hartshorne (USA)**  
*“Mothers and Fathers and Siblings, Oh my!”*
- 3.00 p.m. **End of the conference**

➡ **Consultant for genetics - Prof. Conny van Ravenswaaij (NL)**

➡ **Book exhibition**

#### **Please note:**

All presentations in English will be **simultaneously** translated.  
Interpreters will also be available (if required) for the individual interviews with CHARGE experts.  
For a communication without **barriers sign language interpreters** will be on hand (German sign language).

### CHILD CARE:

|                  |                       |
|------------------|-----------------------|
| <b>Friday:</b>   | 1.30 p.m. - 6.00 p.m. |
| <b>Saturday:</b> | 8.30 a.m. – 6.00 p.m. |
| <b>Sunday:</b>   | 8.30 a.m. - 3.00 p.m. |

### The following extended items will be offered as a part of the child care:

- Craft stations run by a team of Gerrit Event Concept
- High wire course, climbing wall run by a team of Erlebnisspezialist.de (Martin Becker)
- Soap bubble and button station held outdoors (Friday and Saturday)
- Mini soccer competitions
- Swimming course for swimmers and non-swimmers under direction of life-guards in the indoor pool of the youth hostel (advance reservation)

**Sufficient qualified staff will be available, supported by sign language competent persons**

### SUPPORTING PROGRAM:

- Photo blue-box-station for your special souvenir photo (Friday and Saturday)
- Workshop for grand-parents (on Saturday, 2.00 p.m.)
- CHARGE sales-booth
- Tombola
- Book table with literature on the CHARGE syndrome
- Poster exhibition
- Video shoot „10 years of CHARGE Syndrom e.V.“ – a film team will accompany the weekend
- Relaxing massages (physical therapists)
- **Special guests on Saturday!**

## Program for young people with CHARGE-syndrome

### Friday, June 17<sup>th</sup>, 2016

in the afternoon      **Activities with the team of Erlebnisspezialist.de (Martin Becker)**  
or possibility to attend the lectures (see program CHARGE-conference)

6.00 p.m.                Dinner  
7.30 p.m.                **Family introductory session, campfire bread (bannocks)**  
**and get together**

### Saturday, June 18<sup>th</sup>, 2016

The film crew accompanies the young people throughout the day.

10.00 a.m.              **Claudia Junghans, President (Germany)**  
**We celebrate 10 Years of CHARGE Syndrom e.V.**  
Review and milestones

11.00 a.m.              **CHARGE Adult Panel**  
**“My life, my wishes, my aims”**

12.00 o'clock        Lunch

2.00 p.m.              **Round of talks** moderated by Maren Drewes

4.00 p.m.              The **film team** accompanies the group of young people with CHARGE

6.00 p.m.              Festive Italian Buffet  
7.30 p.m.              Live music with „**Max und der Plancke Wahnsinn**“

### Sunday, June 19<sup>th</sup>, 2016

09.00 a.m.              **Round of talks** moderated by Maren Drewes

10.30 a.m.              **Activities with the team of Erlebnisspezialist.de** (Martin Becker)

For a communication without barriers  
**sign language interpreters** will be on hand during the weekend!

### **What else can be done?**

- Photo blue-box-station for your special souvenir photo (Friday and Saturday)
- You can also visit the stations of GERRIT-Event-Concept (Friday and Saturday)
- Airbrush-tattoos (on Saturday evening)
- Relaxing massages (Physical therapists)

You are also welcome to join the lectures (translated by sign language interpreters).

## 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 offtopics 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.

**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 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.

**Lecture by Jeremy Kirk (UK)**

***“All you ever want to know about sex hormones, preparing for puberty and sexuality”***

All you ever wanted to know about sex hormones, preparing for puberty, and sexuality in CHARGE! Dr.Kirk will cover investigation of pubertal problems and optimal hormone replacement, achieving the best results whilst avoiding unacceptable side effects. Dr. Stratton will present on the development of sexuality from identifying body parts to preparing for masturbation. Specific teaching tools will be presented to help your son or daughter with CHARGE better understand the changes to their body.

**Lecture by Dr. Gail Deuce (UK)**

***„Development of friendships in school”***

It is recognised that many children and young people with CHARGE struggle to develop meaningful relationships with their peers. Gail will share some of the findings of her recent research studies that highlight the need to address this issue in the school setting. Some practical suggestions will then also be shared to support the individual with CHARGE to develop these relationships.

**Lecture by Prof. Dr. Tim Hartshorne (USA)**

***“Mothers and Fathers and Siblings, Oh my!”***

A child with CHARGE syndrome clearly impacts all the family members, but little is known about exactly how. This presentation reports on research conducted by the CHARGE lab on the experience of mothers, fathers, and siblings of children with CHARGE, and then discusses the findings in the context of family systems. It concludes with some thoughts on family wellbeing.