

## Program / 3<sup>rd</sup> Professional Day

### Thursday, 21<sup>st</sup>, June 2018:

- from 12.00 o'clock                      Arrival and lunch (snack)
- 2.00 p.m.                                      **Claudia Junghans, President (Germany)**  
Official welcome and information
- 2.30 p.m.                                      **Lecture by Dr. David Brown (USA) & Prof. Tim Hartshorne (USA)**  
***“CHARGE Syndrome and Behavior: Diagnosis and Intervention (Part I)”***
- 4.00 p.m.                                      Coffee break
- 4.30 p.m.                                      **Lecture by Dr. David Brown (USA) & Prof. Tim Hartshorne (USA)**  
***“CHARGE Syndrome and Behavior: Diagnosis and Intervention (Part II)”***
- From 6.00 p.m.                              Dinner and get together
- 7.30 p.m.                                      **Interview with Valeria Risi (Germany) and Tanja Rack (Germany) - two CHARGE families**  
***„My child with CHARGE Syndrome“***  
An insight into everyday life from the view of a parent

### Friday, 22<sup>nd</sup>, June 2018:

- from 7.30 a.m.                              Breakfast
- 9.00 a.m.                                      **Lecture by Dr. Nancy Salem-Hartshorne (USA)**  
***“Behaviors and OCD “Why does my child do that?”***
- 10.30 a.m.                                      Break
- 10.45 a.m.                                      **Lecture by Dr. Gail Deuce, Sense (UK)**  
***„Managing behavior in the classroom“***
- 12.00 o'clock                              **Official end of the Professional day, lunch and departure**
- from 1.30 p.m.                              Start of the 12th German CHARGE conference***  
***We recommend to visit these lectures, too.***

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

## Program / 12<sup>th</sup> CHARGE Conference

### Friday, 22<sup>nd</sup>, June 2018:

from 12.00 o'clock	Arrival and lunch Start of individual meetings with the CHARGE experts
2.00 p.m.	<b><u>Claudia Junghans, President (Germany)</u></b> Official welcome and information
2.30 p.m.	<b><u>Lecture by Rob Last AM (Australia)</u></b> <b><i>"Friendships, belonging and connection"</i></b>
4.00 p.m.	Break
4.15 p.m.	<b><u>Lecture by Prof. Dr. Tim Hartshorne (USA)</u></b> <b><i>"Five hints for new and seasoned parents"</i></b>
From 6.00 p.m.	Dinner
7.30 p.m.	Family introductory session, campfire bread and get together

### Saturday, 23<sup>rd</sup>, June 2018:

from 7.30 a.m.	Breakfast
10.00 a.m.	<b>CHARGE Adult Panel</b> <b>„My life, my wishes, my aims“</b>
12.00 o'clock	Lunch
2.00 p.m.	<b><u>Lecture by Dr. David Brown (USA) &amp; Prof. Tim Hartshorne (USA)</u></b> <b><i>"CHARGE Syndrome and Behavior: Diagnosis and Intervention (Part I)"</i></b>
3.30 p.m.	Coffee break
4.00 p.m.	<b><u>Lecture by Dr. David Brown (USA) &amp; Prof. Tim Hartshorne (USA)</u></b> <b><i>"CHARGE Syndrome and Behavior: Diagnosis and Intervention (Part II)"</i></b>
6.00 p.m.	Dinner
7.30 p.m.	Get together and public broadcast soccer world cup

**Sunday, 24<sup>th</sup>, June 2018:**

from 7.30 a.m. Breakfast

9.30 a.m. Lecture by Dr. Gail Deuce (UK)  
„Managing behavior in the classroom”

**Parallel**

9.30 a.m. Lecture by Prof. Conny van Ravenswaaij (Netherlands),  
Dr. David Brown (USA), Rob Last AM (Australia)  
„Basics on CHARGE-syndrome - compactly”

10.30 a.m. Break

10.45 a.m. Lecture by Christian Winter, (Germany)  
„German care insurance – payments, changes and questions”

12.30 o'clock Lunch

2.00 p.m. Lecture by Claudia Junghans (Germany) and  
Dr. Julia Benstz (Germany)  
“Reflection on the lectures - questions”

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).

Gefördert durch die  
**Aktion**  
**MENSCH**  Sparkasse im Landkreis  
Neustadt a.d. Aisch - Bad Windsheim



**CHILD CARE:**

<b>Friday:</b>	1.30 p.m. - 6.00 p.m.
<b>Saturday:</b>	8.45 a.m. – 6.00 p.m.
<b>Sunday:</b>	9.15 a.m. - 2.30 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
- gold panning sluice 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)
- First aid courses for children and other interested people (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)
- CHARGE sales-booth
- Tombola
- Book table with literature on the CHARGE syndrome
- Poster exhibition
- Caricaturist (on Saturday 05.00 pm – 09.00 pm)

## Program for young people with CHARGE-syndrome

### Friday, June 22<sup>nd</sup>, 2018

in the afternoon	<b>Arrival</b>
6.00 p.m.	Dinner
7.30 p.m.	<b>Family introductory session, campfire bread and get together</b>

### Saturday, June 23<sup>rd</sup>, 2018

10.00 a.m.	<b>CHARGE Adult Panel</b> <b>“My life, my wishes, my aims”</b>
12.00 o'clock	Lunch
From 2.00 p.m.	<b>Swimming course</b> with Udo Waldorf and <b>Mini soccer competitions</b> with Markus Schlemmer and René Löwe
6.00 p.m.	Dinner
7.30 p.m.	Get together and public broadcast soccer world cup

### Sunday, June 24<sup>th</sup>, 2018

09.00 a.m.	First help courses with Susanne Schlemmer
10.30 a.m.	moderated <b>Round of talks</b>

**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)
- Caricaturist (on Saturday 05.00 pm – 09.00 pm)
- You are also welcome to join the lectures (translated by sign language interpreters).

## Information / 3rd 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.

***Please note that if you would like to take part in the German CHARGE conference following the Professional Day and need an overnight stay, this would be connected if necessary with a move in another hotel / inn. The families with a child with CHARGE syndrome have priority for the accommodation in the youth hostel. We would like to draw your attention on the fact that neither in the youth hostel nor in our hotel contingents there are enough single rooms available.***

### Meals (beverages not included):

<u>Thursday, June 21<sup>st</sup>, 2018:</u>	Lunch (Snack)	<u>Friday, June 22<sup>nd</sup>, 2018:</u>	Breakfast
	Coffee break		Lunch
	Dinner		

### Participation fees:

Each participant:      **90,- € without room** (incl. participation fee and dinner on Thursday or lunch on Friday – beverages not included)

**115,- € including room**  
(incl. participation fee, full board – beverages not 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.

### Registration:

Please return no later than **March 31<sup>st</sup>, 2018**

### Contact Organization:

Mrs. Claudia Junghans  
info@charge-syndrom.de / Tel: 0049 (0) 9104 / 826 345 / Fax: 0049 (0) 9104 / 826 345

## Binding Registration

3rd Professional Day on the CHARGE-Syndrome - June 21<sup>st</sup> to June 22<sup>nd</sup> at Oberwesel

Please return no later than **March 31<sup>st</sup>, 2018**

### 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.

Others: \_\_\_\_\_

### Participation:

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

I need a room

single room (June 21<sup>st</sup> to 22<sup>nd</sup>, 2018)

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: \_\_\_\_\_

**Binding Registration - 12<sup>th</sup> CHARGE Conference 22<sup>nd</sup>- 24<sup>th</sup> June, 2018**

Please fill out this registration form and return it by no later than **March 31<sup>st</sup>, 2018**.

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	

We need rooms for \_\_\_\_\_ **adults** and \_\_\_\_\_ **children**  baby bed (only limited number available)  
 from \_\_\_\_\_, June 2018 until \_\_\_\_\_, June 2018 = \_\_\_\_\_ nights

**Arrival:**

- Thursday, 21<sup>st</sup> June, 2018, approximately** \_\_\_\_\_ o'clock (for additional costs please see back page)  
 **Friday, 22<sup>nd</sup> June, 2018 approx.** \_\_\_\_\_ o'clock

**We would like to:**

- attend the **grandparents' seminar** on Saturday, 23<sup>rd</sup> June 2018 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 **"first aid" course** for children and teenager (from 5 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: \_\_\_\_\_

**Additional Information:**

- I'm a professional  I'm a student

**Personal data:**

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

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

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

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

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



## INFORMATION ON THE CHARGE CONFERENCE 2018

### 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.
- 150,00 €** = 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, June 21<sup>st</sup> 2018** 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.

### 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

- 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>, 2018**.  
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.

## Speakers:



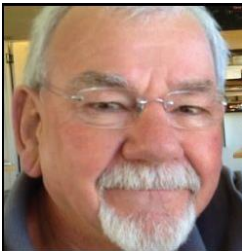
**Dr. David Brown**  
Deaf blind Educational Specialist,  
California, USA.



**Dr. Gail Deuce**  
Deaf blind Educational Specialist,  
UK



**Prof. Dr. Tim Hartshorne,**  
Professor of Psychology, Central  
Michigan University, USA



**Rob Last AM**  
Teacher of the Deaf,  
Member of the General Division of the Order of Australia  
Melbourne, Australia



**Dr. Nancy Salem-Hartshorne**  
Assoc Prof of Psychology  
Delta College, Michigan, USA.



**Prof. Conny van Ravenswaaij, MD, PhD (Consultant)**  
Clinical geneticist  
Groningen, Netherlands



**Claudia Junghans,**  
President of the German CHARGE Family Support Group  
and mother of a 14 year old son with CHARGE  
Emskirchen, Germany



**Dr. Julia Benstz,**  
Vice president of the German CHARGE Family Support Group  
and mother of a 18 year old daughter with CHARGE  
Heidelberg, Germany



**Christian Winter,**  
Journalist specializing in social law  
And aspiring lawyer  
Heidelberg, Germany

## Abstracts

### Lecture by Dr. David Brown (USA) & Prof. Dr. Tim Hartshorne (USA)

#### ***“CHARGE Syndrome and Behavior: Diagnosis and Intervention (Part I)”***

Diagnosis of behavior. Individuals with CHARGE are often diagnosed with a variety of psychiatric disorders such as autism, OCD, and ADHD. This session addresses the problem of psychiatric diagnoses in children with CHARGE: what are these diagnoses, why are they given to children with CHARGE, and what problems do they create, and are they appropriate?

#### ***“CHARGE Syndrome and Behavior: Diagnosis and Intervention (Part II)”***

Interventions for challenging behavior. This session describes interventions that can help to reduce the behaviors that often lead to psychiatric diagnoses. These interventions follow the principle that the behaviors are functional for the child given their various impairments. The interventions address issues of pain, sensory processing, and anxiety.

### Lecture by Dr. Nancy Salem-Hartshorne (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 Dr. Gail Deuce (UK)

#### ***„Managing behavior in the classroom”***

Parents and professionals often talk of behavioural difficulties encountered in individuals with CHARGE. Gail will discuss this with consideration to the CHARGE behavioural phenotype proposed by Hartshorne (2011), looking at potential triggers and how we might respond to this in the classroom.

### Lecture by Rob Last AM (Australia)

#### ***“Friendships, Belonging and Connection”***

Over the years in discussions with parents the topic of ‘friendships’ has arisen and the challenges children and young adults sometimes experience in developing and sustaining friendships.

Often, apart from the family, it is the medical, therapy, early intervention and education teams who become the friendship circle rather than kids from the neighborhood.

In this presentation I will explore friendships, belonging and connection.

This will include discussion on diversity and difference, self-esteem and confidence, peer acceptance, bullying, building capability and strategies for nurturing friendships at home and at school.

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

***“Five hints for new and seasoned parents***

Parenting is always challenging, but particularly with a child who has challenges, such as one who has CHARGE. This presentation reviews five considerations for parenting a child with CHARGE.

**Lecture by Conny van Ravenswaaij, David Brown, Rob Last**

***“Basics on CHARGE syndrome“***

This session is especially designed for new parents.

It will be shared with Conny van Ravenswaaij, David Brown and Rob Last.

The main topics are genetic, communication and play and behavior.

We plan to allow plenty of time for discussion and questions.