

**Carolyn Göttker
and
Jonas Junghans**

*Two teenagers with CHARGE
syndrome introduce themselves*

Saturday, June 19, 2021

09.30-11.30 a.m.

**CEST- Central European Summertime
(Germany)**

***“My life, my goals, my
wishes”***

Hi my name is

Carolin Göttker

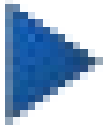


Name / Age / City of Residence / Family

- * Carolin Göttker
- * 21 years old
- * Ostbevern
- * Parents Norbert and Simone
- Brother Mathis (17 years old)
- Dog Balou

CHARGE syndrome in me: *

- * colobomas on both sides
- * Hearing loss
- * No sense of smell



School:

- * Münsterland School in Münster
- * Josef-Annegarn-Schule in Ostbevern (graduation: Realschulabschluss)
- * LEBK in Münster (graduation: higher commercial school)

Work / Internship:

- * Internship in the DRK conference hotel in Münster, perhaps with training prospects.

Hobbies:

- * Ballet & Jazzdance
- * Theater performance
- * choir
- * doing puzzles
- * Spending time with our dog

What I like:

- * Meetings with our family
- * Listening to music / podcasts
- * TV evenings with my family

What I don't like at all:

- * Quarrel
- * Not being honest
- * Not being taken seriously
- * Stupid sayings / looks

I am particularly good at:

- * Being able to listen
- * Put myself in the shoes of others
- * Remember things

What is important to me:

- * Family & friends
- * Honesty
- * Acceptance towards me

My wishes for the future:

- * Health for family and friends
- * To have a job that I enjoy
- * To start a family of my own



CHARGE Syndrom e.V.

Online – CHARGE-Conference June, 2021

Thank you very much for your attention!!! 😊

Hello I 'm Jonas Junghans

Saturday, Juni 19 2021
CHARGE-Online-Conference

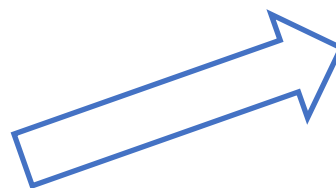


That's me:

- My name is Jonas
- I was born on May 21st 2004
- I have CHARGE syndrome
- I live in Borbath number 29 – thats in Bavaria (D)



7 days old



17 years old

My family:

- To my family belongs:
- Mom, Dad, Juli and Johanna
- Johanna is 9 years old and Juli is 12 years old

My nurses:

- So that I can breath, I have nurses which takes care of me
- Heike goes to school with me
- Kerstin, Angela, Eva, Kathleen and Nina are with me from 10pm until 07 am

This is how I was born:

- I was born in Weimar because I was too early – 6 weeks
- My upper lip was broken because I have a cleft lip and palate
- My esophagus was also broken – that's why I couldn't swallow and had my first surgery on my 2nd day
- Then I could not breathe by myself – so I got my tracheostoma
- I can not hear very well so I have to wear hearing aids
- I can't see well either and I have glasses

My trac:

- I got my trac when I was 4 months old
- I like my trac because I can breathe much better with it
- The trac doesn't hurt me at all
- I can't even feel it
- And it doesn't hurt when I swallow
- The nursers and my mom always clean my trac
- If they take the trac out for a minute I'm no longer afraid anymore
- I want to keep my trac
- Maybe we can try to remove it when I'm grown up – but just maybe

My tube - eating:

- When I was little I couldn't eat at all, so I had a tube in my belly
- I had to vomit a lot
- When I was 3 years old I was able to eat oral and we removed the tube
- Then I ate only mashed food for a long time

Eating:

- When I was 8 years old I ate a „Milchschnitte“ (milk slice) for the first time
- Now I can eat almost everything, I can't chew meat and I can't eat hard food
- When I chew I can only feel the food in the front of my teeth and not on the side

My back:

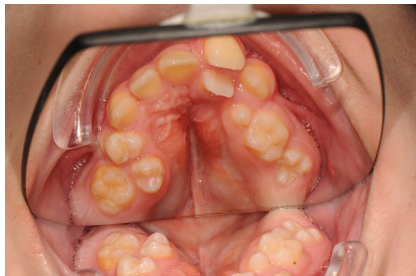
- Unfortunately my back is bad
- That's why I have to go to the gymnastics twice a week
- When I was little I did gymnastics with Maud, then with Thea and now with Stephan

My therapists:

- I had early intervention for the blind with Mrs. Löhnig. She helped me to see. She always brought many things with a light.
- I had speech therapy with Dr. Wohlleben. She helped me to speak and also to eat.
- Then I also used to go horseback riding – I loved that very much.
- And I also had 4 years of occupational therapy.

My teeth:

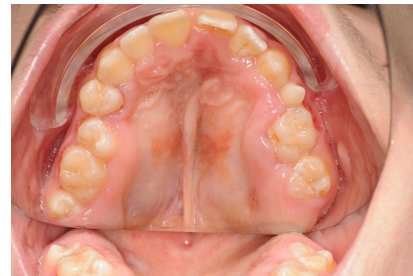
- My teeth were very crooked and I always had to wear braces.
- I had to wear the braces for 3 years
- And I had a surgery on January 28, 2020. They took a bone out of my hip and put the bone in by my teeth.
- I had to stay in bed in the hospital for 1 week and drink with my nose
- Now my teeth are just perfect



Vor der Spange



Die 1. Spange



Nach der der Spange

My beard:

- In order for me to get a beard like my dad, I always have to get an injection every 28 days (testosterone).
- I was very afraid of the injection and my mum always had to hold me tight.
- Now I'm not so scared anymore and I'm very brave.
- I already have a little beard on top and a few whiskers on the bottom.
- And my voice is deeper

Hospital

- I was often in hospital, too
- When I was a baby, I was in hospital for 5 months. Only then I was allowed to go home for the first time.
- Afterwards, I was often in hospital again and had to have several surgeries.
- Sometimes I like being in hospital because I am alone with my mum and can stay in bed.
- But I don't like injections and examinations.

My kindergarten:

- When I was 3 years and 5 months old I started kindergarten.
- It was a regular kindergarten (integration kindergarten).
- I was in kindergarten for 4 years
- It was always very nice in the kindergarten and we sang a lot

My kindergarten:

- Karin was my governess and she had a guitar, which I always liked very much
- There was also always a nurse in the kindergarten.
- First Isy, then Ramona, then Sabrina and then Susanne.

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My schools:

- When I was 7 years and 4 months old I started school.
- My first school was a special school and my teacher was Mrs. Schönfeld.
- I was there for 3 years (I did the 1st class twice and then the 2nd class).
- I learned reading, writing and calculating there.

My 2nd school:

- Then I went into the 3rd grade.
- I went to the primary school in Emskirchen with Mrs. Reitzler.
- I was in primary school for 2 years (inclusion).
- It was very nice there
- Heike, my nurse, was always there and helped me.
- In primary school I also sang in the choir.
- I also joined the class trip to a youth hostel
- And I went on the excursions and ice skating.

My 3rd school:

- Then I started 5th grade at the secondary school in Emskirchen.
- Heike, my nurse, came with me again.
- Then I was in the 6th class
- And then 2 times in the 7th class, because my old class was always so noisy.
- Now I'm in the 8th grade
- And in September I'll be in the 9th grade and then I'm done with school

My 3rd school:

- Middle school is nice, but when my old class was always so noisy, I didn't like it very much
- There is a girl in my class called Milena. And Milena is in a wheelchair because she can't walk and she can only move one arm.
- It is nice to work with Milena because it is so much fun.
- Milena also has a school assistant who is Barbara.

My 3rd school:

- At school we do maths, German, work on the computer.
- We also do manual work
- We do religion and art

My 3rd school:

- We have also sown flowers
- Now I am taking care of the raised bed in the greenhouse.
- I also like to make posters and give small lectures

My English:

And I'm learning a bit of English too

David and Rob have also visited me at school

I can already say in English:

"How are you?"

"When is your birthday?"

"My name is Jonas."

"I am 17 years old."

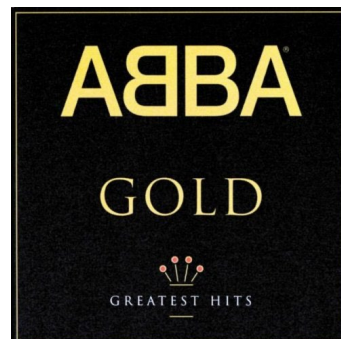
"My birthday is in May."

My 3rd school:

- And the **most important** thing is cooking.
- We cook every Friday. Always with Heike, Milena and Barbara.
- We cook pancakes, noodles with tomato sauce, Kaiserschmarrn, hedgehog and bear muffins, pizza, burgers.
- In December we also make biscuits.

What I like:

- I like playing the piano
- I like to sing
- I like listening to music - for example ABBA songs, Beatles songs
- I like dancing very much
- I like playing Nintendo
- I like calendars - I have 7 calendars in my room



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Yoga:

- In the last year when it was Corona, I always did yoga.
- Johanna, my sister used to help me
- But now I only do it sometimes

Cooking and Baking:

- I think cooking and baking are great, because I can find new recipes.
- I got a cookbook for Easter
- For my birthday I got 2 cookbooks and a cooking course. I can cook online with Heike (a different Heike than at school).

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Holidays:

- I think holidays are great, because we always go away.
- We were in Italy in 2020
- In 2019, we were in Australia and visited Rob and Wayne.
- In 2017 we went to Orlando and saw the Minions, SpongeBob, Mickey Mouse.
- On holiday I always write a diary so I can remember everything we did

What I don't like:

- I don't like to read story books - but I like to read books with recipes.
- I don't like to go out - but I like to go out with Johanna
- When I have done something stupid, I don't like to get into trouble.



What's important top me:

- It is important that people look at me when they talk to me.
- I always want to know and have everything explained to me, because otherwise I don't understand it.
- It's important for me to be able to look at everything very closely, because otherwise I can't see it.
- It's also important for me to have my baseball cap on because otherwise the sun blinds me so much.
- And when I run, I always want to hook myself because otherwise I'm afraid of falling down.

WICHTIG!

Important

What I want to do when I grow up:

- When I grow up, I definitely want to live alone. But I still need my nurses to help me. But mum and dad shouldn't be there. But they are allowed to visit me. And then I cook for Mum and Dad. And of course for Juli and for Johanna too.
- Actually, I wanted to drive a car when I was 18, but unfortunately I can't because my eyesight is too bad.
- I would like to work on the computer and help people. Or I could also try working in a kitchen. I would definitely like to work from Monday to Friday and always 5 hours. I don't want to work 8 hours because that's too much for me and I need a break.





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Thank you very much for listening!
Now you can ask me or my mum questions.

And many greetings to dad, Juli and Johanna
who are at home watching.