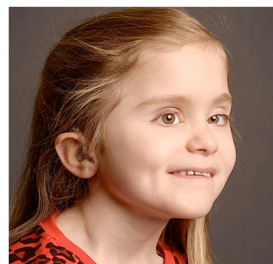


ANDREA WANKA

You taught me...

Partner competencies of professionals
from people with CHARGE Syndrome



CHARGE Syndrom e. V.

Deafblind International CHARGE Network

FOREWORD

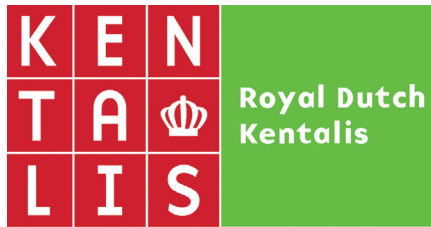
This collection of stories provides a unique insight into how people with CHARGE Syndrome from around the world have lived their lives and touched the professionals they have gotten to know. CHARGE Syndrome is the most common cause of congenital deafblindness and a true multi-sensory impairment. The booklet was initiated by members of the Deafblind International (DbI) CHARGE Network; one of several specialist networks that support the core activities of Deafblind International. The DbI CHARGE Network is an interdisciplinary network composed of teachers, intervenors, educators, therapists and doctors, among others. Whether you work with children or adults, you are welcome to join. We are also open to interested parents, grandparents, other relatives or friends, and to people with CHARGE Syndrome themselves. We believe that sharing knowledge and experiences in this field is critical to our success. For more information on the Deafblind International CHARGE Network, please contact the chair of our network, Andrea Wanka (wanka@ph-heidelberg.de).

The DbI CHARGE Network would like to thank:

- the people with CHARGE Syndrome and their families and supporting professionals who contributed to this book of life stories!
- the people with CHARGE Syndrome who have touched and taught us as professionals.
- CHARGE Syndrom e.V. (www.charge-syndrom.de) and the Marie-Louise Geissler Stiftung for supporting the DbI CHARGE Network in developing this booklet.
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ROYAL DUTCH KENTALIS

At Royal Dutch Kentalis



We have a special team for CHARGE syndrome. Different specialists work together in this multidisciplinary team. We can be involved in assessments, give advice, provide special education and care. We made a (never complete!) list of all the positive qualities of children with CHARGE syndrome.

A child with CHARGE faces a lot of difficulties and challenges in daily life. However, persons with CHARGE syndrome are masters in overcoming those challenges in their own unique way. They are creative, humorous, active, regulative, expressive and enthusiastic. Observe their qualities and take care for their needs. Laugh, love and live together and help them develop.

C: A child with CHARGE is CREATIVE in finding solutions to COMPENSATE! CLEAR CONCEPTS give insight in a world that is often CHAOTIC for them as a result of the multi sensory impairments. CONCRETE LEARNING EXPERIENCES are essential to give meaning to the world around them. Children with CHARGE can be very COMMUNICATIVE hereby visual and tactile COMPONENTS can help them. They love to be IN CHARGE and they are often very CHARMING.

H: A child with CHARGE has lots of HUMOR! Social behaviour could seem a bit odd, but children with CHARGE love to be in CONTACT. They are HELPFUL and love to surprise you.

A: The level of AROUSAL changes constantly in children with CHARGE. An ACTIVE, positive mood can change not on purpose to ANXIETY, fatigue and stress any moment. Starting, continuing and closing ACTIVITIES can become more easy by giving them some more time, visual support and tactile input to complete activities in a positive way. It is an ADVENTURE to be in CHARGE

with them and they love to show their AFFECTION.

R: A child with CHARGE needs REST and REGULARITY, this gives structure and lowers stress levels. REPLACE yourself in their situation and give a child with CHARGE the time and support to REGULATE their mood, sensory input, thoughts and actions! READABLE.

G: A child with CHARGE is often GOAL DIRECTED! They often are excellent in finding solutions for their everyday challenges. GIVE them those opportunities to do and focus on their GOOD qualities.

E: Children with CHARGE love to EXPLORE the world and the people in it! They are full of ENERGY and being with them will never give you a dull moment. A child with CHARGE can be EMOTIONALLY UNBALANCED and needs you to help regulate EMOTIONS. You can help by changing the ENVIRONMENT and EXPLICITLY mention and EXPLAIN certain social situations.

The child with CHARGE is the EXPERT about his own possibilities and chal-

lenges. Look at and talk with the child and the parents to EXPLORE how to adapt as good as possible.

ARWEN

We would like to introduce Arwen, a young girl with CHARGE syndrome.



First her parents tell about her life, then one of her teachers does and finally her communication coach who supports her in her home situation.

Parents:

Arwen is (our daughter of) 7 years old and lives together with her father, mother, older brother Tristan

(10 years) and younger brother Twan (3 years). She is a tough, smart and happy girl with much perseverance. She really knows what she wants. She has humour and is very enterprising and curious.

In her first years of life Arwen visited a daycare centre, but we thought she could develop more. So four years ago we decided to go to the Kentalis CHARGE team in Sint Michielsgestel in the south of the Netherlands. Arwen had several tests and they confirmed Arwen has the potential to learn. Visiting this team was the best choice we had ever made. After the assessment period we have chosen for the Kentalis Guyotschool in the North of the Netherlands and she has been visiting this school for three years now. We, as parents, have chosen this school particularly because of their knowledge of the CHARGE syndrome.

Four years ago homesupport has started by Ingrid Beijaard. She is a communication coach who thinks along with us and also sees the same

potential in Arwen as we do. She helps us to find the right people, and she coordinates that all the people who are involved with Arwen communicate in the same way. She also taught us how we can microanalyze the communication and behaviour of Arwen and how we can respond this.

We love to see the development Arwen has made since she started at school. There they stimulate her in all areas. She has been transformed from a passive girl into a real girl, already 7 years old, starting to communicate, making signs, learning to play and also loving to work hard and to accomplish her tasks. She likes to learn new things and loves to go to school.

In the future Arwen will need care. But we hope she will learn a lot and be more independent. Hopefully she can communicate more in signs and/or with voice, and most of all we hope she can stay a happy and joyful girl with her sense of humour. Parents with a child with the CHARGE Syndrome should follow their heart. It is important to have assessments / tests carried out by specialists who are familiar with this syndrome. Our

kids can develop more than expected and you should never give up!

Teacher Marga Leefkens:

Arwen has a lot of great qualities, she is a very happy, studious girl and she likes to be challenged. She benefits from a sensory diet. She loves to learn new things and also likes to repeat things she already knows. She is fond of singing, puzzling, sorting out all kinds of materials and she likes to learn new signs. She has started to repeat (parts of) words, by voice and with signs and remembers the tunes of a song very well. I have been working with other children with the CHARGE Syndrome for 7 years, did my masters study about one of them and I am a member of the Dutch CHARGE team. Since September 2018 Arwen has been in my class. Having knowledge of this syndrome is an advantage to recognize small signals and to grasp their behaviour, which could be very normal for CHARGE children. It is always a party to work with Arwen, especially when she copies something you showed her, then we do it together and from then on she

shows it on her own. When she is humming afterwards, we are on the right track.

Contact with parents is very important and it is very nice that they share how Arwen is acting at home. Especially when parents send me pictures or a video which we can show in the classroom, giving Arwen and me the possibility to share her daily adventures. It is a challenge to adapt her learning materials in a way she really can learn from it. So we use tactile materials and stay close to her proximal development.

Communication coach in home-situation, Ingrid Beijaard:

I have met Arwen while she was still visiting the day-care centre. When I met her, I saw a girl that was curious about what I was doing with the video camera. Going together on a discovery led to a bond where she would sit against me.

Analysing the video, we first saw a passive and cautious girl with a slow processing speed. Focussing on the little signals and reactions we discovered that she knew exactly what was going to happen and she anticipated. I have been working at

Kentalis for 32 year with children, youth and adults with deafblindness, also with CHARGE Syndrome. Since I work with Arwen and her parents I am also one of the members of the Dutch CHARGE team.

When Arwen was going to the Guyotschool in Haren, I started with supporting her at home. That was very thrilling for her parents. Would Arwen show everyone what she was capable of, like she did within the CHARGE-research?

This girl made huge progress on school and at home. The most progress at home was made by showing the parents what Arwen was capable of and this changed the expectations of the parents. In this way her behaviour changed, she could enjoy things when she was understood and she tried to explore without trouble or hesitation.

With the collaboration of school, we challenged Arwen a little more every time, and what she showed us was surprising. I still remember the first time we made new activities for Arwen to do in the vacation: Arwen was sitting in the beanbag, her mom showed the intention of the activity, making a beaded necklace. Arwen

took over the necklace, pushed her mother away by saying: 'I can do this myself!'

I find this behaviour very typical for Arwen. She is capable of doing things on her own by studying/observing other people doing the same activity. She also did this with tricks on the trampoline. After observing at her own pace, she was able to do the tricks herself. She taught herself to walk on the trampoline and after this she could also walk on the ground. Of course her parents take care for her and challenge her in a positive way. She needs time and goes at her own pace.

Her parents wanted a good, specialized residential home for Arwen, where she can have contact with other children and see good behaviour, and a program in which the communication matches her level. She needs teachers and caregivers who believe in more capacity, despite the fact that she sometimes can't show us.

Arwen's parents have chosen for a residential home of Kentalis for her: everything within one organization in which everyone speaks the same language.



She visits the Guyotschool and stays in the residential home of Kentalis, two times a month, in the North of the Netherlands. Also the contact with the communication coach is needed. The most important is that all who are involved with Arwen work together and act the same. They need to see her potential and can observe and see little signals. The communication coach takes care for collaboration and has an overview of all the agreements that have been made. Working together gives Arwen the possibilities to develop and supports her to communicate which is needed for her to be in charge and to develop in the best possible way!

CHRISTIE

One of my school days – through my teacher's eyes

During a school week, I walk to school every morning. I don't have to walk that far, I live in a boarding house close to the school.

My name is Christie.

I'm 14 years old and I have CHARGE Syndrome. This means I have visual problems, I'm deaf, I have half-sided facial paralysis, a mental disorder and so on.

I hang my coat on the rack and greet my teacher, Ineke. Ineke kneels, because otherwise I cannot see her face due to my colobomas. I always start using sign language but instead she invites me to use tactile signs. When I enter the school, I'm not always in the mood for a conversation, I just want to say 'good morning'. Then I lay my bag on the table.

Sometimes I need a lot of time to empty my bag. This might be because I need a lot of time for Inner Speech, and also because I want to have a look in my personal agenda. My teacher knows I need this time, and she gives me the opportunity to do so. There are so many topics that keep me busy. For instance, the

weekends I spend with my mother and father, the holidays and the activities with my volunteer, especially when the activity is going to the swimming pool. If I stay in my own 'inner speech bubble' for quite a long time, Ineke slowly keeps coming closer – as close as necessary. Regularly it is necessary that she makes tactile contact in order to engage me in my school program. However, there are also days I do everything within a few seconds! My teachers will have to adapt to my varied pace all day.

After I've emptied my bag, I place the chair in the music circle and take my seat. Immediately I like to sing a song with my classmates and teachers. I don't like it if that's not possible. Ineke approaches me to tell me that she notices that I want to start singing, but that I have to be patient and wait for my classmates. If I can't be patient, I sometimes start to scratch or pinch her hands. She tells me that she doesn't like that, that it hurts her. It's hard for me to take her perspective, but I'm improving. Sometimes I am able to



stop, but most of the time my stress level is too high. If she sees and feels that, she tries to apply 'deep pressure' to my body.

I like the routine of the music circle. First, we talk about which day and month it is and then we sing a few songs. As a result of my deafness, I cannot hear or sing the songs, but I love to sign my favorite songs. As time goes on, I start to learn which songs are my classmates' favorite songs. After Ineke and I have a conversation, I often start to talk about the same topic: the different colors of the lamps in the swim-

ming pool for instance. Ineke and her colleagues presume that I do so for a certain reason; that I don't have the ability to initiate a conversation about other topics or because this topic is a safe way for me to start a conversation. It's funny, but after she supports my initiatives, I seem to feel more comfortable and am more open to her reaction. She often expands on this topic in many different ways. Other times she introduces another topic. More increasingly, I like to talk about many other topics.

I might need a lot of time to process. Ineke always tries to figure out

how much time I need. She won't give me too much time because otherwise I might forget the topic we were talking about (well, this is her hypothesis...).

Sometimes it's difficult for me to follow her initiatives, and sometimes she cannot follow mine. We need a lot of time to clearly express what I want, because it is difficult for me to express what is on my mind. However, during the last years I often succeeded to express my thoughts or wishes. Subsequently, we were both very happy for that. It is so special to share these moments. If I'm not able to sign my thoughts and wishes or point them out in my special 'point-book (filled with pictograms and drawings), she offers me paper and a pencil. I have a lot of drawings clear in mind. But as a result of my limited motor skills I cannot make a drawing on my own. However, if my hand is supported by my teacher's hand, I'm able to draw to express myself.

In the beginning of this school year, we made a daily schedule of my school program. I learned the schedule within a few weeks. So, I don't have to look in it every day. If there are changes, it is important for

me that these changes are discussed with me in a one on one conversation and further elaborated visually in my schedule, my agenda or conversation book.

As my mother always says: 'C. has a memory like an elephant', and she's right. This is also the case for a lot of events that happened years ago, and I still remember. But, as I already said I don't have the ability to express myself easily, which is why it is important for my communication partners to know my personal story.

If I'm stressed, this can be seen in my behavior. For instance, I can hurt myself and someone else or I might break something. It is so hard for me to control myself. This can also be for several reasons as commotion around me, my need for clarity, or to get my things to go my way. My behavior can be difficult to understand for my communication partners.

My teacher's opinion is that I need a program with activities within a well-known frame. That at times, I need to be challenged and have a variation in routine. Though there may be certain moments that I require a lot of routine. It also takes a balance of effort and relaxation.

Also it can help me a lot if a certain closeness is provided.

In my program there are two breaks during a school day; to eat fruit and bread at school. I often put both the fruit and bread in my mouth at the same time, completely stuffing it. Pressure and a tap on my cheek by my communication partners might be helpful. Deep pressure massage is also part of my program, many times during a school week. But sometimes my need for pressure is so high, that I ask for an extra session during the day. My teachers cannot always execute this immediately because of other students in my classroom. That's difficult, but although I can understand what they mean – I can consider it rationally. But emotionally, I feel I often don't like to wait....! But it is helpful if my teachers make me feel heard. That feeling is connected with the bond I have been able to build with my teachers.

At the end of a school day I pack my bag and I greet my teacher, Ineke, by saying: *'Till tomorrow'*.



SEM and DAMIAN

Interview Sem and Damian



Sem and Damian are two Dutch boys with CHARGE Syndrome. They are thirteen years old and in their first year of secondary school, the Guyotschool of Royal Dutch Kentalis in the North of the Netherlands. They were very excited to hear about this interview. How great would it be to be mentioned in a book about CHARGE and to become famous! Damian and Sem were willing to tell about their life at school with CHARGE Syndrome. The questions were asked by Marga Leefkens, their former teacher of the primary Guyotschool.

Marga: Do you know what CHARGE Syndrome means?

Sem: Yes, I know that it means that you have all kinds of things. For example; you can have disabilities, facial palsy, cleft lip and so on. And you cannot hear and see very well. They call it deafblind.

Damian: I am deaf and I don't have hearing aids.

Sem: And you don't have a cochlear implant (CI).

Damian: Yes that's right. I am using the Dutch sign language and I wear glasses. When I was young I could

not see very well, but with glasses I can see more.

Sem: Yes, me too, with glasses I can see more.

Marga: Does it also have something to do with balance problems?

Sem: Yes it has, but I can ride a 2-wheel bicycle .

Damian: I also have balance problems and that's why I ride a 3-wheel bike.

Marga: I also have another question: there are also some kind of private things?

(Sem and Damian discuss their visits to the hospital and seeing the doctors, but they asked me not to write about it in the interview).

Marga: Do you two notice more things you have in common or differences between the two of you?

Sem: Damian has different ears and I have a hearing aid and CI.

Damian: Yes, and my face is different, one half is paralyzed and the other is normal.

Marga: I am very proud of you, you both can tell me a lot about yourselves and about CHARGE.

Sem: Yes, we are serious.

Damian: Yes, sure we are.

Marga: For how many years have you been attending the Guyot

school and for how many years do you know each other?

Damian: For 9 years. First I went to the Guyot primary school for 8 years and now I am in the first class of the secondary school.

Sem: I first visited another school and after that I came to the Guyot primary school for 3 years. Right now I am in the same class as Damian.

We know each other for four years now. We are in the same class for the second year now.

Marga: What do you like at school?

Damian: I like math.

Sem: I like history.

Marga: What is difficult at school?

Sem: The mobility lessons outside, where traffic is involved are difficult, because I have to pay attention to all directions. If I want to look over my shoulder, my bike moves another way (like this: making the movement of his bike).

Damian: The Dutch language is difficult for me.

Marga: Question for Damian - what do you like about Sem?

Damian: For example when we talk together and make jokes and when we play outside.



Marga: Question for Sem - what do you like about Damian?

Sem: I also like to talk together, make jokes and play outside, because we have this in common, don't we Damian?

Marga: What kind of toys do you like?

Sem: I like to build with Lego.

Damian: I like to play with the Wii.

Sem and Damian: We both have a computer and most of all we like to play with the iPad, because we can connect on Facetime and make jokes.

Damian: I like the game Roblox.

Marga: What do you like to eat?

Damian and Sem: Pancakes and pizza!

Marga: What would you like to do in the future?

Damian: I would like to do the same as my mum does, working with peo-

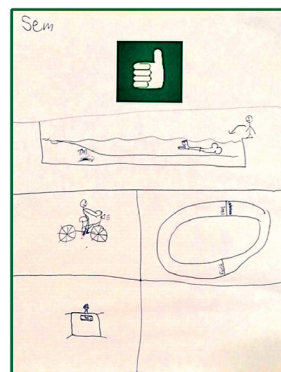
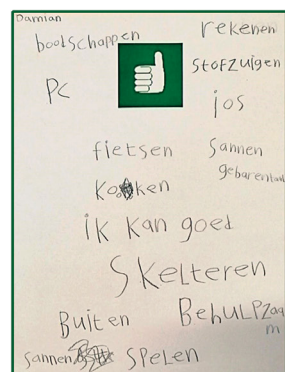
ple and on the computer. I would also like to become a teacher.

Sem: I would like to become a carpenter, like my dad. I would like to go to Amsterdam with him and work there.

Marga: What would you both like to say to the other children with CHARGE Syndrome all over the world?

Sem: I'd like to say that it is nice to know that there are more children with CHARGE in the world.

Damian and Sem: We wish all the others with CHARGE the best. If you persist you can learn a lot, you can learn how to walk, how to ride a bike and how to swim. At first, new things can be difficult, but if you carry through you will succeed. We wish you all happiness for the future.



My name is Bianca.

I was born on May 29th, 1987. I live in Germany. I live with my parents. During the week I visit a daily structure for deafblind people. I have CHARGE Syndrome, which was diagnosed at the age of 23.

My CHARGE features are:

Eyes:

Chorioretinal coloboma, on bothsides, blind.

I use two different glasses, a normal pair and a pair of prescribed sunglasses. Several times a day, I need a horny skin care product, because of my corneal clouding and corneal curvature.

Ears:

Right ear: almost deaf, since 2011 I am wearing hearing aids

Left ear: normal hearing

Heart:

At the age of eight months, they found a medium-sized hole in the left atrial septum, which was closed by itself.

I also get a daily hormone pill because of cycle supportive and osteoporosis - prevention.

To get along with my handicap and



to minimize behavioral problems, it is necessary that I take risperidone every day.

Just by being surrounded of noises, foreign voices, many people or foreign people I feel overstimulated. In those situations, I hurt myself, I scratch my mouth, or I bite the back of my hand. I do that to enforce my will.

Foreign people, my care takers, my family, have already felt how insecure I feel, how difficult my lack of communication and my feeling of being misunderstood is. Because I pulled their hair very hard. Often without warning or recognizable reason. That's why you should take the advice of my parents seriously,



rather than dealing with me and not paying attention to self-protection. You better wear a hood, or even leave the seat free next to me. And do not judge me for my behavior.

Every little piece of information about me should be exchanged between all those who deal with me. But please don't do so in my presence, because I do not like that at all.

What else should you know about me?

When I eat, it is important to know that I need small portions. Because I eat and drink very quickly and I'm not able to recognize when I'm full. I also can't see how full a glass is, I always drink everything at once.

I like ice cream, cappuccino, Coke and hot wine punch, or sometimes a liqueur. I don't know anything about the effect and danger of alcohol, but I like it for my perception.

I feel uncomfortable when we drive a car, in a bend or if the driver has to brake. I'm always afraid and say: „Oh, man!“ or I squeak.

I often complain of abdominal and headache, but without really having any complaints. This is my way to communicate excitement and anxiety.

What I like most:

Fun parks, ferris wheel, carousel, candy floss, I love to go there every day and communicate these four words in an endless loop.

New Year's Eve, fireworks, sparklers in the garden, barbecue and steak, swimming and diving, even in the bathtub.

Walks with and without my dog even if it's stormy, raining and snowing. I like the snow in my face.

I love to swing, jumping the trampoline while lying down and listening to music. However, when I listen to the music I get impatient when there is a pause between the songs.

I can sing well, I like to sing children's songs from my childhood, usually only the first lines of the text. I sing very loud, no matter in which place or in which situation I am.

I'm able to take over small tasks for example breaking spaghetti when we are cooking or gardening (cutting branches). I like shopping, spending free time together, watching my niece and nephew, zoo visits or just a walk in the woods.

I like to be kept busy. Sometimes I have to be motivated and sometimes not. Without help and motivation,

I'm not able to do any activity - I'm too dependent.

I love traveling with the „Lebenshilfe“, for this I need a personal care taker.

What I do not like at all:

Over- as well as under-demand, boredom, waiting times, being sensory overloaded, cutting my toenails.

If I do not feel understood, I repeat my two-to-three word sentences or show a different behavior.

Luckily I'm using a talker since 2016. It allows me, with the help of my family and my care takers, to talk about my day in my own words.

This is very important to me, so I can talk about my work in the daily structure, tell about everyday experiences, my travels and about ME. I am complimented for it and that is important for me to get recognition, even if it's just for small things. I have a good understanding of the language, not profound, but easy language. Of course with the talker, my parents also learn when things are not going so well in my daily routine. I tell them with the word „ANGRY“.

Today I barely have health problems and I never had a surgery.

What it means to have the CHARGE syndrome? I really do not know because I have never lived a „normal life“. I am full of joy, laugh a lot and make others laugh.



AMELIE

My life with CHARGE

I was born in 2004 on a rainy spring day together with my twin brother. Mum and dad told me later that before birth they already have had fear that something could be wrong with me because I had a cardiac defect and mum had incredibly lot of amniotic fluids. Therefore, we were born by caesarean section.

With my facial nerve paresis and my special formed right ear mum and dad immediately saw that I was not healthy. Now I wear my hair long and my face has become a lot nicer. On my second day of life I had an esophagus operation. I had problems with drinking for a long time afterwards. With a special bottle, mum and dad had to practice with me many hours, so that I could drink a part of my milk myself. For the rest of the food I got a PEG tube when I was three weeks old. Now, finally, I could grow a little bit and increase my weight.

Unfortunately, my right nostril had also become overgrown. It was opened when I was 12 months old. For this I had to sleep for eleven days, so that I would not pull the

tube from my nose.

Because I could not move so well like others, mum practiced with me every day on a special orthopedic pillow. When I could finally stand firm at the age of one and a half, I thought this was great! However, I could walk independently at the age of four years. Since then I wear a protective helmet, so that my Cochlea implant does not break if I push myself somewhere or if I fall. I got the CI when I was two years old and since then I am able to hear much better than I could before with the hearing aids.

When I was little, I had to survive eleven surgeries and 14 anesthetics. Thank goodness I do not remember this time anymore. Even now I still have many medical appointments, which annoys me quite a bit. I have to go to the endocrinologist because I need growth hormones and now also estrogens, so that puberty starts. Then I have to go to a child neurologist because, unfortunately, since 2012, I have had epilepsy, which limits my independence. Always someone has to take care of me. It's frustrating. I would like to go shopping alone with

my girlfriends or go to the movies or just stay somewhere else during school vacation. But that's not possible because of the seizures.

Also, every now and then I have to go for a heart check and every two months I go to the ENT-specialist, because my tight ear canals have to be kept clean. I am also very bothered that my nose is running all the time since my operation. I have to blow my nose constantly, otherwise I look like a little red nose.

Of course, I still have to go to the audiologist to check the CI and so we have an appointment almost every week, which I don't like a lot.

Thank God I go to a great school that a lot of disabled kids attend. There, the lessons are tailored to us and we can also get all our therapies during school hours. In the afternoon, I visit a day-care center, which is also located in our school. Then a bus takes me home.

On Fridays I go to a sports club nearby. There we work with a circus silk dangling from the ceiling. That's a lot of fun for me.

In my free time I like having contact with my girlfriends via WhatsApp or ride a kettcar, a scooter or my

bike outside. I also like trampoline.

In particular, I am happy when we go on holiday. Then from time to time we go skiing or cycling. I don't like hiking that much anymore, but if I can still go into the pool in the afternoon, I also let myself be persuaded to hike, because swimming and diving is my great passion.



Here's how a painter painted me at a CHARGE conference

MAXIMILIAN



Maximilian was born in 2010 with CHARGE Syndrome and all associated medical problems. After being in an integrated nursery school and kindergarten, he is now attending the local elementary school. He is very well integrated in his class and very popular.

Conversation between Maxi and his mom:

Maxi, do you know what CHARGE means?

Yes, it is a syndrome, with various body malformations. Every letter represents a malformation.

And do you know what you have?

Yes, I can only see with one eye. The eye has very low vision. The second eye is a glass eye. Unfortunately, I

can't recognize faces.

I also have difficulties with hearing, so I wear hearing aids.

I can't walk so well because my vestibular system does not work.

I can't speak very well. Not everyone can understand me. That's why I'm going to get a tablet with voice output.

Maxi, which school are you going to?

I'm going to elementary school Veerßen in class 3a. I have various things to help me, for example a screen reader and an FM-system for hearing as well as my school assistant Inka.

Do you like to go to school?

Yes, I like the teachers, my girlfriend and all subjects except swimming because I do not want to jump into the water.

What do you usually do in your free time?

I play a lot on the tablet (listen to radio plays, watch science shows, or play knowledge games) but I also like card games.

Do you like to play and meet other children?

No, not very often – only when the other children ask me. But I am often invited to children's birthday parties.

Do you also know other children with CHARGE Syndrome?

Yes, we visited another boy and his family and we met many others at the CHARGE conference.

What is your favorite food?

My favorite food is apple pancakes. Actually, I like to eat everything. Although I had a tube through my stomach for a while after I was born.

Maxi, what would you say to other families who are newly confronted with CHARGE Syndrome?

I would tell them that they do not have to be scared!

From Maxi's mother:

Maximilian is a very happy child. He has difficulties with changes, when appointments are canceled or lessons in school are changed. This can lead to very long discussions.

He basically talks a lot, especially when he is very busy on topics. He is not able to stop that. These moments are always very exhausting especially for us as parents. Due to the extreme difficulties in pronunciation, listening to him is extremely stressful.

Over the past eight years, we learned that we parents have to fight

very hard for our child's well-being. Often, our persistence has been rewarded.

Meeting and talking with other affected families is very helpful because it shows you that you are not alone. Although all children with CHARGE Syndrome are different, these parents are in the same position and able to understand our concern and problems.

We sincerely wish all new CHARGE families all the best!

Maximilian and Susanne

Maxi's school assistant wrote:

School life with Maxi is as colorful as a rainbow. Bright colors surround the great days, dark colors the not to great days. Maxi usually gives us the bright colors; like joy, curiosity, cooperation, kindness and, to some extent, empathy.

The dark colors such as restlessness and lack of effort are kept in the background. It is a pleasure to see how he loves his school lessons; every day we experience new small and big „school miracles“, coupled with a general development in the activities of daily life.

JONAS

Classroom aid

When I first met Jonas he was 7 years old. I had no previous experience in dealing with children with CHARGE Syndrome or in the field of deafblindness. I am a nurse for adults and have several years of experience in nursing services. Since I am a mother of two children, I always had a lot of fun supporting children. And I knew I was able to cope with this new challenge.

I started to support Jonas in the middle of his first year at a school for special needs. I was his medical school helper because of his tracheostomy. First, we had to get used to each other, which worked surprisingly very fast and very well. His cheerful, social and unbiased nature made it easy for both of us. Quickly, I was able to adapt to his repetitive behavior and could react in a calm and consistent way.

One of my tasks is to help Jonas with all challenges in his everyday school life. I sit next to him in the classroom and support him during the teaching process, adapting all the learning content and doing all



organizational tasks for him. Jonas often processes difficult situations in school life by withdrawing to a protected place or refusing to perform his duties. Jonas feels the need to belong and to get attention. However, his way of communication – verbally and non-verbally - with others is sometimes hard to understand. Depending on the problem, I have to discuss the situation with Jonas in simple and understandable language. And I have to explain the possible consequences of his behavior to him. For example, I have to explain in detail how his behavior affects others. I have to

say that Jonas is always motivated to continue working by encouragement and praise. And he shows himself very reasonable, friendly and loving.

For Jonas, I am often like a mouthpiece to his classmates. I try to stand up for his concerns and to facilitate mutual understanding. In doing so, I try to guide Jonas to act independently in similar situations.

With the respective teachers I have to discuss his individual learning subjects and I also try to support them.

Since Jonas is able to express himself well in simple language and can also hear quite well with his hearing aids, I have the opportunity to talk to him about school and all situations a lot. This takes a lot of patience, because he has to ask the same questions over and over again. He also wants to hear many things over and over again and changes in his usual routine have to be explained again and again.

Due to his visual impairment, Jonas needs a magnifying screen, large-sized worksheets or special materials for teaching.

It needs consideration, because seeing and recognizing is sometimes

very exhausting for him and he gets tired pretty fast. Therefore it is necessary to adapt unnecessary visual stimuli, too small texts and pictures or things that are difficult for him to see.

This requires constant intervention, adaptation, anticipation and recognition of his receptivity, which depends on his daily form. Jonas is a very compassionate boy who also likes to console other people. It is very important to him that others are feeling well.

As soon as he feels that I am not feeling well, he asks what's going on and we talk about it in detail.

Jonas and I have always had a very good relationship of trust and he always relies on my assessment and guidance. Nevertheless, I encourage him to make his own decisions and to implement them as well. If I praise him and tell him how proud I am, he is very much motivated.

Over the years, I've learned a lot from Jonas. He is able to be happy about little things and successes. He is often very patient and undemanding. His friendly and cheerful nature makes it easy for me to look forward seeing him every day.

Interview with Jonas

I am Jonas. My birthday is May the 21st, 2004. I am now 15 years old.

Jonas, do you know what the CHARGE Syndrome is?

CHARGE children have hearing aids because they can't hear. And they have glasses because they can't see. And they also have a tracheostomy - but not all. And sometimes they need help.

Do you need help too?

Yes, but only sometimes.

And when do you need help?

For example, with my homework. When it's difficult. If it's easy, I can do it alone. I need help with cooking and eating, cleaning up and at school.

At what age did you come to school?

When I was 7 years old.

And which grade did you start in?

In the first grade.

Can you remember your teacher?

That was Mrs. Schönfeld.

And how long have you been there?

I think for only 2 years or something like that.

How did you like it?

Fine.

Was there something you did not like?

No, I do not remember anything.

And after that you came to which school?

After that I went to elementary school. My teacher was Mrs. Reitzler. I stayed there for 2 years.

What did you like in elementary school?

I liked the learning a lot. And I was in the choir - that was nice.

Was there anything you did not like?

No, everything was fine.

And then you went to which school?

Then I went to middle school to Mrs. Herbolsheimer.

And in which grade you are right now?

In the seventh grade.

And is there something you like?

I think the school is nice.

And is there something that you do not like so much?

No nothing.

What are your hobbies?

My favorite hobby is playing the piano and the guitar and listening to the radio and playing with my sister.

Is there anything you are very

good at?

I can dance very well. I also cook very well. Nothing else.

Is there anything you are not so good at?

No, I'm good in everything.

Is there something you do not like?

Reading, because I do not like that. Because I do not always understand everything I read.

What do you like most?

I like to listen to music and the radio and also too news.

Do you have friends too?

My girlfriend is Alida and my sister Johanna.

Would you like to have more friends?

Yes, I would like to have more friends.

And what do you want to do with your friends?

Play, eat together, and listen to music and dance. And I want to have fun with them. And go to school with them.

Do you have a friend at school?

No, not really.

Would you like to have a friend at school?

No, no. Because I can't decide who I would like to have. And it's so hard and exhausting.

Would you rather have a CHARGE friend?

Oh yeah.

And do you already have one?

Yes, there is Christian and there is Lavinia.

What do you usually like to play?

6 takes, SkipBo and City, Countries and rivers

And when you grow up, what would you like to do then?

When I grow up, I would like to drive a car. And I would like to live on my own. And also work. Working, I want to write on the computer and help people. And also help cleaning. And also help tidying up.



CÉLIA

Parents

For us the most important thing is to be patient, to be patient with Célia, to always take the time to show her everything we do, to show her what we want her to do, to continue to talk to her even though she can't hear us, and to try to understand her reactions. The most important thing is to be patient. Don't expect her to do everything you ask her right away. You need to give her time, often she responds later, maybe unexpectedly but she will react. Sometimes it seems that Célia doesn't initiate contact, that she is not looking for others, but there will be a moment that she will initiate something, in her own time, all by herself.

Célia is very clever, she can understand everything, but that takes time. She knows when her environment is safe, and she knows when there is danger. It is important to always be patient with her. Always show her where we are going, explain to her what we are doing. You mustn't move her unexpectedly because it will be difficult to guide her afterwards. When we change her diaper in a hurry, and if we want



Célia to play with us afterwards, we will lose time because she will still be processing the diaper moment.

When she was little we made the mistake to insist on her drinking, while she knew already that she would need to vomit, and maybe it is for that reason that she doesn't want to drink anymore. The most important for Célia is to take everything very slowly. The same, when Célia is a bit annoyed, it is important to let her be, she will calm herself. We will be next to her, but we won't take her into our arms if she doesn't want that. However, that is what we do with other babies when they are crying. With Célia it doesn't work that way. She can get frustrated, she doesn't want to be touched at that moment, she will calm herself and

then she will accept being touched. When she is feeling irritated she can even start kicking her feet.

We shouldn't compare her to other children because they are all different; every child develops in its own way. Célia's development can go forward and backward, she can learn some new behavior, and then she doesn't want to do it anymore, and after a while she will redo it. She was capable of standing, and then one moment she refused. We think that we are taking a step back in her development, but in fact no, she is going forward. She needs her own time; she has her own process of development. If she wants something, she wants it, if she doesn't want something, she doesn't want it. She, for example, has learned a new sign, then for a couple of days she doesn't use the sign anymore, and then she uses it again after a period. We need to give her time.

We film some activities to show what Célia can do, what games she can play, to show her capacities. During medical exams, she may not doing what she is asked to do, but we know that she is capable. If you want her to do something immediately,

it is not certain that she will do it. If you want to see the Célia's abilities you will need to observe her for one day or more. She can have days that she doesn't want to work and she can have days that she can show you everything!

When we are going to the hospital for a medical exam, we think that she recognizes the place. She needs to familiarize herself with her environment; she needs to have confidence. If she doesn't feel secure, she needs to be with familiar people. She recognizes the hospital, because she becomes restless. She has learned that after a medical exam, often something happens that she doesn't like: getting a vaccination, taking some blood, etc. That is why it is important to give her the time to calm down, to make her feel safe, that we won't pressure her; we will take it slowly.

According to the doctors, Célia doesn't see much, but to us she can see very good because she is very tactile. She doesn't like to wear shoes because she wants to feel contact with us. If she doesn't have to wear trousers, nor other clothing, she is very happy.

Célia is 4 years old, she loves the water, she loves physical contact, she loves playing. It is funny, because sometimes when she has played a lot during the day, we say to each other that she is dreaming, she is rethinking her activities of the day. She loves to be tickled, she loves it a lot. At first she didn't like it at all, but step by step she learned to recognize it and to love it.

Lately she is doing some new activities. She stands on her head; she is initiating contact. Célia, when she is outside, loves the wind, in fact she loves it always when something is touching her skin. She doesn't like teddy bears very much; she prefers hard objects. She is a bit afraid of empty space, she needs to be in contact with something. Célia learns very fast.

Célia needs to wear glasses, but in the beginning she didn't want to. So we started with giving her her glasses every day in her hands, for a little while. In the end she puts on her glasses herself, but she still refuses it when we want to put her glasses on. It is important for her to have the control herself. We need to avoid forcing her to do things, or to

take her somewhere unexpectedly. It is important to inform her, also about things she doesn't like, if not she will lose trust in you and you will need to start all over again. After she had a heart surgery, it took about 3 months to see her smiling again. We were afraid that she would never be the same, it was really difficult. She was very upset and we thought that she had lost something. We gained the functioning of her heart but it seemed that we had lost Célia. But then, after 3 months she came back. We needed to explain to the nurses to take it slowly with Célia, sometimes we took over to show it to them. Now they understand.

Célia is very curious, she will come to you to be in contact, maybe not immediately, she will take her time.

Sometimes we think that she doesn't understand a sign because she doesn't respond right away, or because she does the same sign in different ways, but if you give her the time you will see that she really understands. We have noticed that she herself also makes new signs. For example, she can pull at her sweater to say that she is feeling warm.

Our message is to not be afraid of the future!

Professionals

When we met Célia, we didn't really connect right away. We didn't understand her behavior, and she didn't understand ours. It was necessary for us, with time, and with support of those who already knew her, her parents, to get to know Célia. Learning more about CHARGE Syndrome, getting in contact with people who have met other persons with CHARGE Syndrome, and also the exchanges we had between us, were of great help to better understand Célia.

Thus we have learned to read between the lines of her hands, her eyes and her back. For example, we have learned that when she covers her eyes, it is to avoid light that is too uncomfortable, too painful maybe. That when she lifts her eyes, it is her way of looking at you. That turning her back to us, is not a way of avoiding us, but rather showing us she needs to process the time we spend together. So in the case of Célia, lifting her eyes means seeing

us, turning her back means hearing us. With time we have changed our view of ourselves and our view of her, which allowed us to really meet.

"With time": if there is any important notion to keep in mind, it is this one, time. This notion of time cannot be compared to anything. It is not time that makes us hurry in the morning, it is not time that makes us worry when we are too late, it is time that makes things possible. It is time that gives hope. It is time that made it possible for us to see every little miracle that happened one by one: the first hand that was placed on our face, the first smile, the first sign. The look, time, hope. That is what Célia taught us, that is what we rediscovered.



Célia and her brother.

BORIS



Mother

Boris is an “ordinary” boy of four years old. He has a mutation of the gene CHD7 and so they say he has elements of CHARGE Syndrome. It causes abnormalities in his ears. He doesn't have semi-circular channels, and his autolytic system doesn't function which causes big problems with his vestibular. He doesn't have auditory nerves so hearing aids won't help: we use tactile sign language to communicate with him.

In the beginning we were more focused on his deafness but now we have started to realize that his balance problems are much more important. At the age of 1 year he could not keep his head still, he was constantly seeking balance. He made his “first steps” laying on his back on the ground and pushing himself forward with his legs. We helped him, until he was about 2 years old, to walk by holding him by the waist, but he could fall over any little obstacle and he didn't know how to break his fall with his hands. That's why we gave him a little helmet because he often had little bumps....

When he wanted to move to another place, he came looking for our hands and then he would take us there where he wanted to go. At the age of 3 years old, he could walk by himself. This little miracle happened during the first 3 weeks after he started to go to school. He followed the other children in his class who were turning around in circles. That was a big relief for us - and for our backs! Now he is able to run, to jump, but he can't walk straight and he still falls often. His balance problems cost him a lot of energy. He often needs to rest

his head to conserve his energy: he plays while lying back on the ground, he holds us when he has walked too long, or he holds his head while sitting at the table. We have even observed that he puts his trousers on with his head on the ground and his bottom in the air. This might seem a bit odd, but for him this positions helps him to better concentrate.

We have noticed that he can see better when his head is supported. He doesn't have a visual problem, but he misses a lot of visual information because of his stabilizing issues; that is why he is having difficulties with fixating. He had learned by the age of 18 months to use some signs. When he started to walk he completely stopped using signs and he still rarely uses signing; His balance has improved.

He is a little guy who is curious, and very tactile. He explores his environment by touching everything and by using objects in a different way every day. He loves taking objects with him, little cushions, little pawns, a little cotton twine, and then he will take off and discover lots of new things with his treasure of that moment.

Surprisingly, Boris loves strong sensations: very high slides, swings, the trampoline...he likes the speed. He also likes to discover new environments. Sometimes he can have a particular behavior and they often ask us if it might be autism...it is difficult to categorize. He is a child with CHARGE Syndrome and that is it.

Boris goes to a school for deaf children. Every morning he goes there with a big smile on his face. We hope that he will succeed in using sign language so that he will be able to communicate with his environment and that he will develop to his full potential. This will come one day, together with his balance.





Special teacher

What have I learned from Boris? To have met Boris, has helped me to adapt my way of teaching deaf children, taking the time, giving time to the children to observe, time to stabilize their body and their focus, time to discover and to adapt to the environment, time to handle, to experience, to construct and to process.

But above all, I need to give myself the time to observe, the time to understand his experiences, the time to exchange with him without moving on to something else, giving him the time to come to us, the time to express himself with his look, his mimic, and his signs...by giving him the time, real interactions can take place and special moments of togetherness arise.



Laci Faith was born July 2, 2006, five weeks early, at 3lbs 15 ozs. Matthew and I felt ready and excited to be parents. We had been married for five years, gone on a lot of crazy adventures, and endured a year apart while Matthew served a 15-month tour in Iraq. We felt strong and accomplished in our marriage, but we wanted a baby with whom to share our lives.

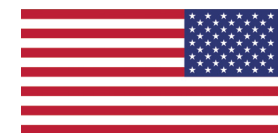
Laci is our first child and despite all our other personal adventures, she is by far our biggest challenge and our greatest accomplishment. Laci was born with a complete bilateral cleft lip and palate, microphthalmia, bilateral colobomas, two holes in her heart, pulmonary stenosis—and

a huge desire and will to live!

At first sonogram, we hoped to find out the sex of our baby... we left that visit knowing “she” would have birth defects. We knew we had four months to get ready for our baby—who would need cosmetic surgery to repair facial birth defects, a cleft lip and palate. The news was frightening but acceptable, and everyday we grew more anxious to see our little one.

Laci was born on a Sunday night and started life with a helicopter ride to the neonatal intensive care unit (NICU)—with her Dad. Laci was beautiful at birth; her facial defect was different than we had imagined, but had no gaping holes. It was repairable. The excitement and emotions we felt were unexplainable... it was as if we were the only people in a NICU full of babies. We did not want to leave Laci’s side; we took photos of her everyday!

Our excitement was very short lived. We soon began to realize Laci was one of the sickest babies in the NICU, who would have multiple setbacks before going home. Each day more specialists were added to the management of her care.



My thoughts centered on how do we take care of this child? Laci was unable to take a bottle and decisions were made to give her a G-tube. Her prognosis for sight was poor, and we soon learned she failed two hearing tests. Happy thoughts of motherhood were once again taken from me. I feared for Laci's future.

Three surgeries and a little over two months in the NICU, we brought our baby home for the first time. A lot of equipment came with her, but she was finally home with us. The first year of our lives was filled with tears, heartache, worry, hospital stays and prayer. Laci's middle name, FAITH, became more than just a name, but something to live by. Our faith was tested; we asked "why"... a lot. But before our eyes, as we understood our role as parents to Laci, she grew stronger.

Another cleft palate procedure was performed in 2008. The partial success of this repair allowed her to start eating by mouth; she is now taking all meals that way. Drinking is still a challenge, so we supplement when needed. (Laci's final palate repair is scheduled for March 2019—which will be surgery #29.) Her he-

art has also been repaired and she is currently on no medications. Laci was given the diagnosis of legally blind in December 2006, but has demonstrated different skills. She reached for things handed to her, loved light and played with purpose. We introduced her to sign language in December 2008; she learned new signs every day. Laci attended Sunshine Cottage (i.e., school for the deaf, parent/infant program) from April 2007 until she graduated from 5th grade there in August 2018. Laci was fitted with hearing aids and gave us wonderful feedback to her joy of the ability to listen and hear sounds. She had a successful cochlear implant surgery in August 2007 on her right side; a left implant was impossible, due to lack of an auditory nerve. In the summer of 2008, Laci received the official diagnosis of CHARGE.

Some of you reading this may have more challenges with your children, some of you fewer. I can say that many of Laci's diagnoses have been difficult, frightening, unbelievable, and seemed permanent—but they have proven not to be. Matthew and I hope you might use our experience and our beautiful

daughter, Laci, to see past those first frightening, disappointing times.

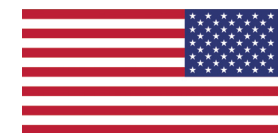
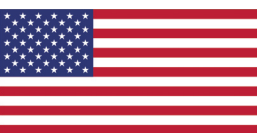
Laci received early intervention services from birth to 3 years of age, which included a variety of related services. Laci started horseback riding in April 2008; she liked to attend the tumbling gym and started swimming lessons in 2009. She walked, unassisted, for the first time February 11, 2009. Laci began preschool in the fall of 2009 and Kindergarten, with her age-mates, in August 2011. Laci loves school, is a joy to be around, and is a little sponge, who enjoys learning. Laci speaks, using vocabulary of thousands of words; her current challenges include articulation. Her favorite foods are oatmeal, milk, ice cream, cereal and avocado. Laci loves books, ani-

mals, babies, playing with others, singing, and princesses.

Laci began attending her neighborhood school for the first time in 6th grade. The transition was almost seamless; Laci has made friends, is doing well academically, is playing the cello in orchestra, and is a member of the STEM, art, and yoga clubs. Her favorite subject is science! Laci will be 13 this summer—a teenager! She'll be getting a new heart valve (surgery #30)—and a phone!

Whatever your journey may be, please use the gifts we're all given. Keep your faith strong, hope for more than you can imagine, and share your love. You will be amazed how strong your children will become, how much they will accomplish, and how much love you will receive.





ANTONIO



Antonio is a 22-year old young man with CHARGE Syndrome. Antonio is preparing for a major transition as he is graduating from his current educational placement and moving to a new living arrangement. He has had a variety of medical, educational, vocational, and living experiences that have helped shape him into an optimistic and resilient young adult ready to face these major changes.

When Antonio was born, he was diagnosed with CHARGE Syndrome,

and he spent a significant amount of time in the hospital. Within the first 3 years of life Antonio had at least 5 surgeries including G-tube placement, heart repairs, and a tracheotomy. In the years following these surgeries, Antonio had fewer medical issues, and he began to grow and develop. During this time, he started walking and began eating orally. As a result, his G-tube and tracheotomy were removed. Throughout the course of his life, Antonio has had a total of 10 surgeries with his most recent surgery occurring when he was 15 years old, and he has had no major medical complications since then.

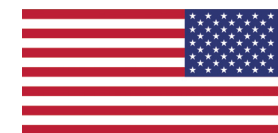
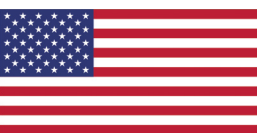
Antonio is currently completing his final year of school at Perkins School for the Blind in the DeafBlind program. He has been a student at Perkins since he was 15 years old. Communication has been difficult for Antonio given his dual sensory impairment, and it has been a challenge for him to learn how to communicate using pictures and sign language. But as he has progressed through school, he has learned how to effectively communicate with others using verbal language, sign

language, and assistive technology. Sign language and assistive technology have been a great resource for him, especially when used to help repair communication breakdowns. Using these modes of communication, Antonio has become a great advocate for himself. He spoke at his high school graduation, and he has spoken at DeafBlind Awareness Day in Massachusetts for 3 years in a row. He has enjoyed attending school at Perkins and especially likes going to school with other students who have CHARGE Syndrome. He is also happy to be around people who understand him and are able to communicate with him. Some of his favorite school memories include making new friends and participating in the track team.

While attending school at Perkins, Antonio has had a variety of volunteer and work experiences. He currently volunteers at Mass Eye and Ear where he helps build informational packets about surgeries. He likes hospitals and enjoys learning about surgeries and different medical procedures. Because of these interests, Antonio hopes to continue working or volunteering in a hospital

or medical setting as he transitions into his new living arrangement.

Antonio has already experienced major transitions in his living arrangement, as he moved to Perkins when he was 18 years old. His goal was to live at Perkins to become more independent. Soon, he will be moving to a new apartment with 5 other individuals and staff support. He is excited to move to his new home, and he has carefully designed his new room and requested various accommodations to help him live more independently. Some of the exciting features in his new home include an orange (Antonio's favorite color) bedroom, a hand-made rocking chair (perfect for playing the harmonica), and extra lighting under the kitchen cabinets (for better visual access). For the future, Antonio hopes to live happily in his apartment and visit his family regularly.



My name is Lance.

I am 20 years old. I live in Missouri, in the USA, with both of my parents, my two younger sisters, and younger brother. I am a senior at my local high school and I will graduate this year.

I was diagnosed with CHARGE Syndrome when I was two weeks old. I have bilateral colobomas of the retina, so I am legally blind, but I can see anything presented to me within four inches of my face. I am deaf and have a cochlear implant with minimal hearing. I started walking independently right after I received my implant. I communicate expressively primarily with gestures, but comprehend a fair amount of manual sign language. I also have a tablet which helps with communication.

I enjoy horseback riding, swimming, looking through a camera lens (I can manipulate the way I look at things) and exploring. I like to visit my grandparents and I am very social. I love learning and sticking to my routine. I like for things to be predictable.



We have a lot of fun as a family. I enjoy being outside and I enjoy interacting with my siblings. We like to travel. I have been to Florida, California, Texas, Iowa, Kansas, Arkansas, South Dakota, Illinois, Nebraska, Oklahoma, Ohio and Indiana. We swim, walk on nature trails, visit museums, ride in boats and go to amusement parks.

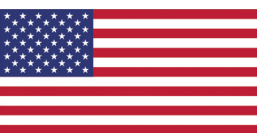
We really like watching and playing in athletic events.

I was fortunate to be diagnosed at an early age because I had a vision teacher coming to my house while I was still an infant. I started school when I was three years old. I attended the Children’s Center for the Visually Impaired and the Therapeutic Learning Center (a school for children who have hearing impairments) through kindergarten. For first and second grade I went to the Kansas State School for the Blind where they had a deaf-blind program. These teachers created strategies to help us learn, which assisted the school districts and how they taught students with deaf-blindness. From third grade through my current senior year in high school, I have attended school in my local school district.

It has not always been an easy path; my parents had to fight the school district in order to for me to attend our local school. Since then, the teachers and service providers have been very supportive. Now we are preparing for transition from high school and trying to figure out what

I can do - whether it is hold a job, volunteer, or participate in other programs. I am excited and scared to know what the future holds!





MATTHEW and BRIAN



Matt and Brian are 22 year-old identical twins with CHARGE Syndrome. They were born premature at 35 weeks old. Within their first few years of life, they were in and out of the hospital for surgeries, illnesses, and intestinal issues. When they were 1-year old, they were diagnosed with CHARGE Syndrome. Their parents worked hard to provide them with all the tools and opportunities necessary to help them grow and develop into 2 independent young men who enjoy gardening, bowling, exploring, traveling, looking at maps, and fishing.

As Matt and Brian grew older they received many therapies and individualized educational programming. When it was time for the two to go to high school, the decision was made to send them to the Deafblind Program at Perkins School for the Blind. The

school was far from home, so the boys would have to live at Perkins. Ultimately, it was a tough decision for Matt and Brian's parents, but they decided that sending them to Perkins would help them to mature, make new friendships, and become more independent.

Matt and Brian have now been at Perkins for roughly 6 years and have had a variety of educational and vocational experiences to prepare them for their lives as adults. They have volunteered at a place called Cradles to Crayons and at the Perkins Braille Talking library. One of their most recent vocational ventures that capitalizes on their interest in exploring the community has been a small business called MurrayPrime. MurrayPrime offers a variety of services to Perkins' staff and students including making deliveries, selling baked goods, picking up lunch, and running errands for staff. On a day to day basis, Matt and Brian are required to go off campus, socialize with people in the community, and adhere to a flexible schedule. These experiences are teaching Matt and Brian to become more independent and preparing them for their next major life transition, which will be leaving Perkins.

IMPRESSUM

editor:



Deafblind
International DbI

Deafblind International CHARGE Network

CHARGE
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