



for parents

VOYAGE TO HEALTH

Hyperinsulinism Germany International consists in three branches

Magdeburg

- Prof. Klaus Mohnike, Pediatric Endocrinology
klaus.mohnike@med.ovgu.de
- Prof. Martin Zenker, Human genetics
martin.zenker@med.ovgu.de
- PD Ilse Wieland, Human genetics
ilse.wieland@med.ovgu.de

Berlin „Frankfurter Tor“

- Prof. Wolfgang Mohnike, PET-CT
nuclearmedizin@berlin-dtz.de

Greifswald

- Prof. Winfried Barthlen, Pediatric Surgery
winfried.barthlen@uni-greifswald.de
- PD Silke Vogelgesang, Pathology
silke.vogelgesang@uni-greifswald.de

We are a group of experienced medical specialists dedicated to congenital hyperinsulinism (CHI). Distributed over three cities in Germany we are communicating closely with each other. Whenever you contact one of us, you meet us all! Once the diagnosis of CHI has been established by your local doctors, you are cordially invited to contact one of us, or, ask your doctors to do so.

STEP 1

Counselling by telephone or e-mail

Because CHI is such a rare disease, your local doctors may not be experienced in this field. As a result, you may feel concerned and isolated. We will show you that there are quite a few families in the world who have shared the same destiny. If you wish, we can connect each other. In any case, we will explain this complex disease CHI to you and present modern therapeutical options. Feel free to contact us at any time. It is our passion to support you!

STEP 2

Genetic investigation

There are some genetic constellations which influence the therapy. All your local doctors have to do is to send 5 ml of blood from each, the child, mother and father to the Institute of Prof. M. Zenker in Magdeburg, Germany:

Institute of Human Genetics

Prof. Martin Zenker / PD Ilse Wieland
Otto-von-Guericke-Universität Magdeburg
Institut für Humangenetik
Leipziger Straße 44
D-39120 Magdeburg
Germany

*martin.zenker@med.ovgu.de
ilse.wieland@med.ovgu.de*

Within two weeks, you will get the results. Then, we will discuss their consequences with you and your doctors. There are three possibilities:

- 1) A genetic mutation typical for focal CHI
- 2) A genetic mutation typical for diffuse CHI
- 3) No known genetic mutation can be identified

In case 1 a PET-CT (see below) is indicated for exact localisation of the focal lesion.

As to the cases 2) and 3) the next steps depend on the response of your child to medication and if the side-effects are tolerable.

However, if it is not possible to prevent hypoglycemias consistently, or if you feel uncomfortable with the daily medication, their side-effects, the frequent glucose measurements or even with the ubiquitous fear of hypoglycemia, then we should consider to perform a PET-CT.

STEP 3

PET-CT in Berlin Frankfurter Tor

It is not easy to perform a PET-CT in a child with congenital hyperinsulinism. For high-performance selective surgery we need a precision down to one millimeter. We have learned to rely only on PET-CT's performed at the Institute Berlin Frankfurter Tor. This center has one of the world's largest experience in CHI, having performed more than 180 investigations in children since 2004, when the PET-CT for CHI came up.

During the performance of a PET-CT, you will meet us all: Prof. Wolfgang Mohnike, director of the PET-CT, Prof. Klaus Mohnike, director of Pediatric Endocrinology in Magdeburg, and Prof. Winfried Barthlen, director of Pediatric Surgery in Greifswald. As a team of highly specialized experts, we will interpret together the PET-CT findings at site. Taking the individual circumstances of your child and all modern therapeutical options into consideration, we will agree to a united proposal about the further treatment. We will explain and discuss the options with you. As this decision is a life event, you may need time to think about it.

There is nothing more that can be done in the world for your child. You will feel it.

Logistics

You will arrive in Berlin by plane one day before the PET-CT at the airport either in Berlin-Tegel or Berlin-Schönefeld. You will travel by taxi (a 30 min ride) to the

„Sana Klinikum Lichtenberg“

Fanningerstraße 32
D-10365 Berlin
Germany
phone +49 30 5518-0
fax +49 030 5518-4004
www.sana-kl.de

There you will get a warm welcome at the reception. They have a huge pediatric department. The child and one parent will stay in the hospital overnight, all the other accompanying persons (who are heartily invited), stay in a small hotel nearby.



STEP 4

Hotel Arcadia, Frankfurter Allee 73a, 10247 Berlin
distance to the Sana Klinikum: 1,6 km
www.arcadia-hotel.de/berlin/the-hotel.html

or Hotel Siegfriedshof, Siegfriedstraße 204b, 10365 Berlin
distance to the Sana Klinikum: 200m
www.siegfriedshof.de

Upon arrival, you will continue the nutrition the way you did at home. Nothing will be changed. The next day you will meet Dr. Michel, who is our experienced pediatric anaesthetist. He will take you and your child in an ambulance to the PET-CT-Center which is in close vicinity to the hospital. He will perform a light anaesthesia to your child during the PET-CT, just enough that the child will not move: Remember, the precision of the images must be down to one millimeter! After the PET-CT the professors will talk with you and explain the results. You and your child are brought back to the hospital where you will spend another night. You will have a lot of time to think about the next steps and we will answer to all of your questions. Take your time.

The PET-CT will show either focal, diffuse or atypical segmental mosaic CHI. Depending on these results and your personal circumstances, we will recommend either restrictive surgery or medical therapy. In any case, we will NOT endorse sub-total or near-total pancreatectomies. A recent publication from the Paris group showed an over 90% rate of diabetes later in puberty, which is not acceptable in our opinion. With highly selective surgery this serious complication can be avoided in most cases.

Surgery in Greifswald (Step 4a) or
Medical Therapy in Magdeburg (Step 4b)

Surgery in Greifswald – Step 4a

If surgery is indicated you will continue your journey directly from Berlin to Greifswald, which is a 240 km drive to the Baltic Sea.

You may take a local train from the Berlin main station. Connections are every two hours. The journey will last about 3 hours. As explained before, the medical treatment for your child will be continued as you did before.

Take a taxi from the main station Greifswald to the University Clinic (a 10 minutes ride).

Clinic for Pediatric Surgery


University Medicine Greifswald
Ferdinand-Sauerbruch-Straße 1
D-17475 Greifswald
Germany
phone +49 3834 86 7037
www.medizin.uni-greifswald.de/ki_chir

There we will wait for you and welcome you. The child and one parent are admitted to stay in a separate room in the hospital.

Accompanying persons (who again are heartily invited) stay in a small hotel nearby.

Europa Hotel, Anklamer Straße 1-3, 17489 Greifswald
distance to the hospital: 200 m
www.europa-hotel-greifswald.de

or: Hôtel Galerie, Mühlenstraße 10, 17489 Greifswald
distance to the hospital 3 km
www.hotelgalerie.de



Surgery will be scheduled few days after your arrival. It will last one whole day, between 8 to 12 hours. Depending on the site of the lesion(s), your hospital stay will be approximately 2 weeks for a laparoscopic surgery and 4 weeks for an open approach. Afterwards, you will return home.

Medical treatment in Magdeburg – Step 4b

If medical treatment emerges to be the best option for your child, then you will travel from Berlin directly to Magdeburg. It is located 150 km south-west of Berlin. The train departs with a frequency of every two hours and the journey lasts two hours. From the main station, take a taxi (a 10 min ride) to the University Clinic.

University Clinic Magdeburg

Pediatric Endocrinology and Metabolism

House 10

Leipziger Straße 44

D-39120 Magdeburg

Germany

phone +49 391 6724000

fax +49 391 6724202

www.med.uni-magdeburg.de/pensw/P%C3%A4diatrische+Endokrinologie+und+Stoffwechsel.html

They will wait for you at the reception of house 10. The child and one parent are welcome in the hospital, accompanying persons in hotels nearby.

City-Hotel, Konrad-Adenauer-Platz 1, 39104 Magdeburg
distance to hospital 5 km

www.cityhotel-magdeburg.de

or: Maritim Hotel, Otto-von-Guericke-Straße 87,
39104 Magdeburg

distance to hospital 3 km

www.maritim.de/de/hotels/deutschland/hotel-magdeburg

In the Pediatric Endocrinology department in Magdeburg a thorough metabolic, endocrinological and neurological examination of your child will be performed. Medical treatment will now be optimized. Expect a hospital stay of approximately ten days. Thereafter you may travel home.

You and your local doctors are strongly encouraged to keep further contact with us in order to optimize the treatment for your child, and to respond to any changes in the long run.



Winfried Barthlen, MD, PhD,
Professor and Director of Pediatric Surgery
University Medicine Greifswald
Ferdinand-Sauerbruch-Straße 1
D-17475 Greifswald
Germany

winfried.barthlen@uni-greifswald.de

phone ++49 3834 86 7037

fax ++49 3834 86 7038

www.medizin.uni-greifswald.de/ki_chir