



## **The Dianino Foundation provides fast assistance for diabetic children**

Type 1 Diabetes is an incurable form of diabetes and is the most frequent form of metabolic disorder among children and teenagers in Germany. It should not be confused with age related diabetes.

Any child can fall ill with diabetes. At this moment there are 25,000 children or teens living with Type 1 Diabetes, that is 1 child in every 600 in Germany. However an area of primary concern is the substantial increase in new cases, as 5 to 6 children are being diagnosed every day.

When children get Diabetes their world changes overnight, not only for the child but their family as well. This is where the support of our foundation is crucial because without the tools necessary to manage this disease, the results could be life threatening. Based on the immediate challenges facing newly diagnosed children and their families, The Dianino Foundation was created with the goal of helping these young patients and families to cope with this new difficult situation.

Thanks to the support of our donors we are in the position to lend help extremely quickly in emergencies and crisis via our child diabetes hotline, our Nannies (Diabetes Trained Nurses and Consultants) and our house of sanctuary.

Together we want to further expand our services so that we can continue to bring back smiles to the faces of more and more diabetic children and to extend our assistance to the families, giving them the energy and courage to face this life-long challenging disease.

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## The illness child Diabetes

Diabetes melitus (Diabetes Type 1) is a chronic metabolic malfunction that is characterized by the appearance of high sugar levels in the blood. The colloquial term sugar illness stems from the fact that an untreated diabetic loses sugar through the urine.

The cause of diabetes in children is a result of a deficit in Insulin, a hormone produced by the pancreas. This malfunction has its origins both in the genetic structure as well as the environment we live in. Diabetes is a so-called polygenetic illness where several genetic factors contribute together.

The immune system plays a fundamental role in this illness. A false signal in the body leads to the destruction of the beta cells, which are responsible for insulin production in the pancreas by antibodies. The time period from detecting these antibodies and appearance of the symptoms of the illness can take up to 10 years. This is because diabetes in children only occurs when 80-90% of the beta cells have been destroyed. The reason why these antibodies arise is still being researched. In a small number of diabetic cases these antibodies cannot be detected. Here the illness is said to be an idiopathic form of diabetes.

When a child's body produces too little or no insulin then this must be regulated by external means. The therapy, which involves injecting the child with insulin, relieves the symptoms of the illness without healing the condition. This external introduction of insulin into the body imitates the natural release function. Here the hormone is administered via so called pens, injections and insulin pumps. It is desired that the child or teenager learn to administer and manage their own treatment, however in all too frequent cases it falls on the parents to take over this role.

### Facts and Figures

Little is still known about diabetes in children among the general public. This is despite the fact that this illness is the most common kind of metabolic disorder in children and its frequency is increasing enormously. In the last twenty years the number of affected children has doubled.

Today in Germany there are over 25,000 cases of diabetes in children and teenagers and most worryingly is the rapid increase of this illness in children under 5 years of age.

The latest findings of EURODIAB study predict a further massive increase of the illness by the year 2020.

## The Consequences

Everything changes as soon as a child is diagnosed with diabetes. The total family rhythm transforms overnight. Diabetes must be strictly treated to avoid damage such as blindness, amputation, damage to the nerve system and kidneys or even going into a diabetic coma. Effective treatment for diabetes requires up to 6 injections during the day and night. This means that by the time a diabetic child reaches 15 he or she will have experienced up to 27,000 injections!

Prior to each injection a blood sample has to be taken to determine how much sugar is in the blood. Particularly small children resist having to take injections because they lack the understanding why this has to be done. The parents of such children have to treat them in this way resulting in a series of nightmare like experiences that can put an unbearable strain on the parent-child relationship resulting in the fact that many such parents experience exhaustion and burnout after treating their children for a number of years.

For those teenagers going through puberty and who suffer from diabetes they often experience significant problems accepting the necessary therapy, resulting all too frequently in fear and feelings of guilt leading to additional psychological stress.

The administration of insulin into the body is only a part of the treatment. In fact changes in diet are just as important. Nutrition must be carefully considered, calculated and prepared. Spontaneous consumption of sweet things has to become a part of the past. For a mother of a four year old diabetic child this can be a huge strain: When my daughter attends a spontaneously organized party in the nursery school and has to sit at the side well behaved but sad not being able to take part in the full festivities and having to eat her own specially prepared food. The strains on the children and the parents are immense. They are characterized by feelings of insecurity, fear, pain and not knowing how to cope in the future.



## The Dianino Foundation

### About us

Ingrid Pfaff founded the Dianino Foundation in 2004. As a mother of a boy, who became ill with diabetes at the age of 7, she has personally experienced the “gaps” in Germany’s care system and knows all too well what help such families need.

With the directors and the scientific advisory board and various donors we strive to improve the life of children and teenagers at the same time supporting their families in times of psychological and social crisis.

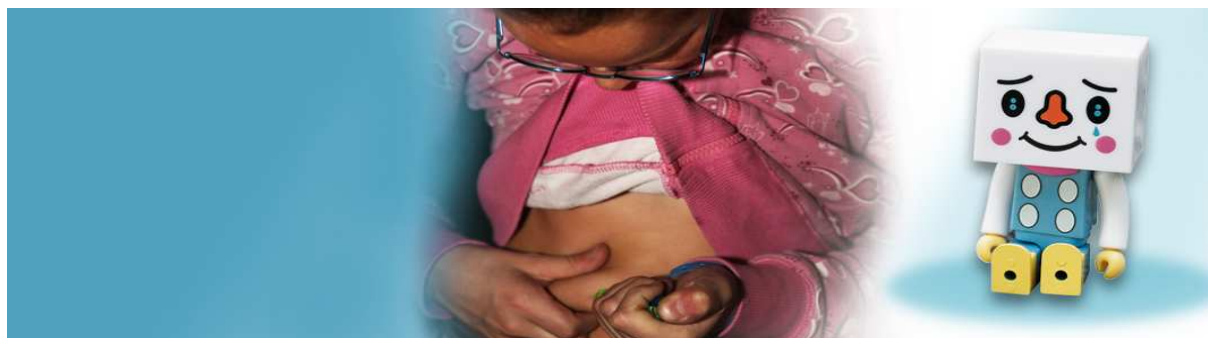
We would like to send out a signal of help to children who have been diagnosed with diabetes and have to live with this for the rest of their lives. We help to give them strength and help to give them back a bit of their childhood.

Once a child has been diagnosed with diabetes nothing remains like it was before. The whole daily routine has to change and the mental damage remains all too often unattended. It is not a rarity that the affected children experience the illness as isolating. Not only do they often feel “different” than the others but are also treated so by the outside world. Such isolation in the nursery and school usually occurs because of a lack of knowledge about the illness and its treatment. The exclusion of the child from excursions, class trips, birthday parties and sport leaves the child feeling even more of an outsider. The consequence is that diabetic children often try to hide their illness, secretly injecting themselves with insulin on the toilet or more dangerously not even having this essential medicine.

Besides the children, their families also often suffer from psychological strain and stress especially in the early days following this serious diagnosis. Insecurity, sadness and the fear of doing something wrong often lead to conflict within many families. Here we want to provide assistance so that such families can return to and maintain a new but secure daily routine.

### Our Tasks

Through our commitment and actions we complement the work of the pediatrician and the diabetes teams and we support the children in their important development phase, helping them to experience confidence and joy in their lives despite the illness. We call on the families at home and stay on hand to help them in this new situation and to give them the courage to go on. We support the parents with the essential side of caring for their children especially in the early days following the diagnosis of the illness.



## How does Dianino help?

### 1. The Hotline

Our Hotline is always open for you on working days. Our Hotline is there to deal with everyday questions in connection with your child's diabetes. With this hotline we are providing concrete psychosocial support. Through hard work and dedication we have a team of Diabetologists, Diabetic consultants, teachers, trainers, psychologists and social workers answering calls and working together to help support the families of Type 1 Diabetic children and teens. Furthermore a number of experienced parents are also on hand to give their advice and assistance.

### 2. Our Diabetes Nanny Project

The Nanny Project is the central help function of Dianino. This unique European project was founded in Baden-Württemberg in 2006 and by the end 2010 had expanded into all 13 German states offering coverage across Germany. Today we have more than 270 Diabetes Nannies working in an honorary capacity across Germany. With approximately two thirds being child nurses and/or diabetes consultants and the other third being parents of diabetic children, teachers and/or governors/ -esses, the project is dependant on the commitment of our staff to utilize their spare time to help children and families dealing with the challenges of Type 1 Diabetes.

The work of the Diabetes Nanny deals mainly with the general situation in the family. She supports them with measuring the blood sugar level or injecting the insulin especially if this is causing fear and uncertainty. Similarly she helps with the contact to institutions such as Nursery schools, schools, day homes and training centres in order to show them and explain in detail the child's disease and necessary management techniques.

Above all special circumstances such as a new addition to the family, heavy strains (illness, death or separation of parents) or even social stress (unemployment, financial difficulties etc) often harm the home treatment of diabetes and drive both child and parents to despair. In such cases our contribution protects children with diabetes from the negative problems and prevents further suffering.

The Diabetes Nannies are extremely experienced in dealing with diabetic children. They should be seen as supplementary to Diabetic-treatment of children and teenagers. They work in close cooperation with the diabetes-team in charge of the treatment and only come when requested by the pediatrician and with the permission of the parents.

## A Typical Nanny Assignment

### 1. A request from a doctor

The doctor recognizes an emergency at a family and enquires with the Dianino Foundation for the assistance of a Diabetes Nanny.

### 2. Assignment of a Diabetes-Nanny

Dianino arranges a Nanny out of the Nanny-Pool who is suitable and lives near to the family.

### 3. Diabetes-Nanny makes contact with the doctor

The Nanny consults with doctor and/or the diabetes-team treating the child in order to best prepare for her assignment.

### 4. Diabetes-Nanny makes contact with the family

After formulating her duties the Nanny contacts the family and discusses her position and role.

### 5. Attending to the emergency at the home

The Diabetes-Nanny calls on the family and helps until things get back to normal.

### 6. Attending the Local School or Nursery

Provide onsite training and support for teachers and careers, as well as educating fellow classmates on Type 1 diabetes and how they can help support the child.

### 7. Documentation for the medical care

The Diabetes-Nanny gives the doctor or diabetes-Team constant feedback to ensure the best possible complete care.

## 3. Events

In an effort to bring joy back into the lives of children suffering from Type 1 Diabetes we also hold a range of events from our children and their families, including Circuses held across the country. The purpose of these events are to surround children with fellow Diabetes children so that for one day that do not have to feel alone with this disease. The event is also a terrific opportunity for families to share their experience and guidance along with the support of some of our outstanding Nannies.



We have received terrific feedback after each event and here is a selection of their kind words:

**Carlos and family (8 years old):**

*Many thanks for a great day. We were overwhelmed by the feeling that Carlos is not the only type-1-kid...Such a day is a really big help and a break from our strenuous daily routine.*

**Ute's mother:**

*An unforgettable day, not only for our diabetic children! The many sparkling eyes full of joy speak for themselves. It was an important, positive experience for our children that they saw they are not the only ones with diabetes. Carry on with your great work! A toast to the forthcoming years and thanks again for the super day and the CD!!*

**Markus:**

*It was suuuuper! I could not stop being astonished, the show and so many children just like me!*

**Lena's mother:**

*It was a very special day for my Lena (8 years old). The very first pleasure trip since she went down with the illness at the age of 4 and that without someone from the family! Just great for her self-confidence.*

**Annabel:**

*It was super day, many thanks! It was good for me to see that I am not alone with this illness.*





## Our Successes

Beyond the Hotline and our annual events, the Nanny project has been the pride and joy of this foundation, and its national impact has been made possible because:

- Word has spread about the commitment and power of our Nannies
- The phenomenal dedication of our Nannies where the annual 73,000 kilometers travelled by our nannies is not seen as a strain but rather the way to our goal
- The several thousand hours spent by our Diabetes-Nannies at homes across the country all with the end goal of reducing the suffering of so many of our “little heroes”
- The assignment of the Nanny is free of charge for the family
- Our commitment to the family both in the short-term and long-term, providing both immediate support but long-term emotional and psychosocial support.

We are truly blessed to have a committed team of 270 Nannies, working for just €30 a visit regardless of the length of time they spend with the families they are each dedicating themselves to a worthy cause and we have achieved wonderful results.

### A Mother's Letter

Dear Mrs Pfaff,

I would like to thank you from the bottom of my heart for allowing sister Elke to come to our house to look after my son Moritz and to show me how to carry out the care for him. Sister Elke is available at any time day and night. I am deeply thankful to be able to have her by my side - always helpful and careful when looking after my son. I can approach her with any questions that may arise which she answers in a professional yet easy understandable way. We are always in the best hands with her. Once again many, many thanks for your help.

### A Nanny's Letter

Dear Mrs. Pfaff,

My visit to Simon (name changed for privacy) brought me so much joy, I had a good inner feeling. There is nothing more beautiful than being able to help another person. As far as Simon is concerned I was the “Super-Nanny”, this he called me, it was great. He wanted me to accompany him straight away into school so that he would feel more secure. This was pure soul-balm for my heart. I am really pleased that I may support the foundation

## Testimonials from the Medical Community

Dr. Thomas Haak, Diabetes Center in Bad Mergentheim:

*“I am involved with Dianino because I know, after having many encounters with parents and the affected ones, that they feel they have been left alone. To have someone at your side, to assist and sometimes reassure you is an enormous help for such families and I am glad that Dianino was founded for this reason.”*

Dr. Karl-Otfried Schwab, University Children’s Hospital Freiburg:

*“I am committed to Dianino because Dianino can offer decisive help for the affected families so that they can handle life better with the illness.”*

Dr. Thomas Hermann, Clinic Prince Regent Luitpold, Scheidegg:

*“I am committed to Dianino because diabetic children and their families urgently need a better lobby in our society, in politics and in the health system.”*

Katrin Hertrampf, Diabetes Center Bad Oyenhausen:

*“I am committed to Dianino because adolescents with diabetes need the support in order to develop just as well as healthy young people of the same age.”*

Dipl.-Psych. Berthold Maier, Diabetes Center Bad Mergentheim:

*“I am involved with Dianino because experience shows that when other problems in a family with a diabetic child arise, help and support is needed. Dianino is always there to help with advice and action both are effective in relieving the parents of their burdens.”*

Dr. Herbert Müller, Children’s Hospital Kempten

*“I am committed to Dianino because I deeply feel for the future of such diabetic children and the affected families.”*

Dr. Antje Herbst, Children’s Hospital Leverkusen:

*“I am committed to Dianino because I know how great the fears and worries can be as a parent of a child or teenager suffering from diabetes.”*

## Story of the month

Every month we celebrate a child that The Dianinio Foundation has supported, and here a selection of their heroine tales:

### Michael Story

Michael has had diabetes for some months. He is keen, motivated and wants to find out everything which will help him to get better. At 9 years old he noticed that he did not feel “right” compared to before, and this was the beginning of Michael’s journey with Type 1 Diabetes.



One of the biggest challenges for Michael was explaining to his fellow classmates that he had diabetes, as he did not want to be constantly the centre of attention and wanted to continue to take part in everything as he did before.

In order to help sooth this transition The Dianino Foundation provided a Diabetes Nanny to both help Michael manage his Diabetes but also to accompany him to school. On one Spring day, together with his Diabetes Nanny they sat down with his classmates to explain the illness. The most important thing that occupied the minds of the boys and girls in his class were the questions... Is it contagious? Will it go away one day? Can I become a diabetic? Can people become unconscious with the illness? With all of the questions came answers and with the help of the Diabetes Nanny Michael’s fears and anxieties surrounding his school friends were eased and Michael could once again feel “normal” at school.

### Jonas’ Story

Jonas is 3 years old and very shy. About 3 weeks ago just as he was in middle of getting to know the new world of nursery school he was diagnosed with diabetes.



In order for Jonas to continue to attend nursery school, it was important that the other children understand what Diabetes was and why Jonas would have to be measuring his blood sugar at school.

In an effort to help his fellow 3-year old classmates, The Dianino Foundation provided one of its top Diabetes Nanny’s and her friend puppet Clara to visit Jonas’ nursery. Reflecting on the experience our Nanny said “together with my hand-puppet Clara I read stories about other small children with diabetes tell them at a child level about the illness.”

The results of this initiative were a complete success as the Diabetes Nanny explained “during my visits to the nursery school Jonas is becoming more and more self-confident, showing the children the insulin pump and how it is used, how and where he should prick his finger and where not. The ice was broken and, for me, another beautiful mission comes to an end”. So together with the help of our team and a courageous young boy we were able to make his days at nursery school bring a smile back to his face.

### **Elias' Story**

Up until now life has not been very kind to 16 year-old Elias. As a small child he was able to see everything in full colour and day-by-day everything slowly started getting darker and darker until one day he was blind. If blindness was not challenging enough, Elias experienced a double blow with his diagnosis of Type 1 Diabetes. Managing both diseases has been incredibly challenging for Elias and his family.

Special moments happen rarely for Elias and all year Elias had been looking forward to the end of year class trip, however as the day approached Elias was rushed to the hospital for emergency treatment due to his strongly fluctuating blood sugar levels. From an instant of his dreams of attending the end of year trip were dashed. This is the exact moment when Dianino was brought in! Elias' sadness was turned to elation when our male supporters of the nanny-project collected him from the hospital, following 2 days of treatment and support from our Nanny the two hit the road so that he could be reunited with his school friends at the school country home.

### **Jasmine's Story**

The year began with a shock for the 11 year old Jasmine. In January she was diagnosed with diabetes, a heavy blow for a girl who lost her mother only one year ago. As a single father, this diagnosis puts insurmountable pressure on a man already raising five children alone. Without any previous knowledge about Diabetes Jasmine and her family need urgent assistance in order to learn how to manage her disease.

The first challenge for the Dianino Diabetes Nanny during this incredibly difficult time is to support her and her father in accepting this illness and training them on how to manage and cope with it. Then the diabetes Nanny accompanies Jasmine to school in order to explain to her teacher and classmates how they can also help Jasmine with her new situation. This is a big relief for Jasmin and her father as he finally has the peace of mind to let Jasmine go back to school on her own knowing she is safe and cared for.

### **Klara's Story**

Every child responds to the diagnosis of Type 1 Diabetes different and for 7-year-old Klara diabetes, particularly the injections, feels like some kind of punishment. In this case her mother is also extremely fearful of hurting her child with the injection needles and trembles every time she has to do it. Unfortunately she cannot turn to help from anyone in her family, as father, sister and grandma have no idea what to do. This mixture of fear and helplessness is extremely common, as no parent ever expects to be testing their childs blood and injecting them with needles on a regular basis.

At this time our Nanny was called in to help this anxious mother to become more confident with the illness. Together with Klara they practiced giving injections to a cuddly toy and slowly but surely Klara mother begins to feel more confident and she learns to understand and accept her illness and above all the reason for the necessary treatment.



## Donate

Type 1 Diabetes touches the lives of over 25,000 children and teenagers in Germany and every day we are trying to reach as many of those children as possible and support them and their families on their journey as they cope and manage with this disease.

Dianino plays a vital role in the lives of newly diagnosed children suffering from Type 1 Diabetes and it is vital that we receive support from at home and our German community abroad so that we can continue to bring a smile back to the faces of thousands of children suffering from this disease.

Your donation will help us continue our work and with your help, we can continue to provide invaluable services such as Diabetes Nannies for children and families and our Hotline , which all provide information and emotional support for people living with Diabetes. Every donation counts, and is used to benefit children with Diabetes, their families and careers.

We really believe that Dianino has an important role to play within our society and here are some of the ways you can help:

### 1. Donations

Every dollar counts and goes right to our most valued helpers, our Nannies. Keeping this program alive is incredibly expensive and without these donations and the help of our valued sponsors, we would not be able to have the means necessary to support the 270 Nannies we currently have!

### 2. Charity Events

Whenever throwing an event, whether it be sport tournaments, bike rallies, company trips, concerts, school festivals or bazaars partnering with a charity or foundation can be a terrific way to give back.

We at the Dianino Foundation are committed to helping children with diabetes and are very proud to connect with companies, groups, organizations and clubs in support of our mission. At Dianino we truly believe that there are many situations where both your personal commitment and ours can be brought together to realize an event or a project. Experience in past has shown that such joint actions often lead to a mutual success for both parties.

Here are two terrific examples:

### **The Rotary Transalp Charity Tour 2012**

The 2012 Transalp Tour is a charity-project of the German Rotary Club Villingen-Schwenningen Mitte. On Sunday, June, 3rd an international group of road bikers started in Villingen for a 6-day touristic tour passing some of the most scenic alpine passes on the way to the Rotarian partner club Bergamo Citta Alta in Italy. All revenues of this Tour will be donated to the Dianino-Foundation, which is supporting families with children suffering from diabetes.



### **Charity Dinner, Ladies' Circle (Germany)**

On September 24<sup>th</sup> a Charity Dinner called "1001 Arabian Nights" was held where guests would pay a fixed price for the food including drinks (donated by sponsors) and the proceeds were donated to Dianino. At the event, the founder Ingrid Pfaff, was also invited so that the guests could find out more about the foundation and its work. It was truly a terrific evening and we were so proud that the Ladies' Circle thought of us!

### **Have you also ideas and interest in doing such a cooperative event for the benefit of the Dianino Foundation?**

We would love to discuss any potential sponsorship or donation opportunities; all you have to do is contact us:

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