

# Working together for siblings

FamilyTies AKTUELL  
Issue 3 | 2012

## Editorial

**Ladies and Gentlemen,  
Dear Friends of FamilyTies,**

"I am very worried because of Maria's diabetes. She doesn't like the needle. What's that all about? It scares me. Will I get that as well?" - These concerns and fears were expressed by 9-year-old Emil, whose sister Maria has trisomy 21. Emil's case is a practical example from the new "LARES Siblings" e-learning, which is featured in detail in this issue.

FamilyTies has been established as a foundation since May 2012. We would like to take this opportunity to introduce Irene von Drigalski, the new managing director. And, of course, winners of the FamilyTies Promotional Award 2012, who were selected for creative and outstanding sibling children projects, again have much to show.

Last but not least, we would like to draw your attention to the next symposium on 15-16 March 2013 in Nuremberg. It is now the third time that an opportunity is being given to exchange ideas and information, network and to discuss new approaches to supporting siblings. So, whip out your pen and circle the date in red on your calendar today!

We hope you enjoy reading this issue.

Working together for siblings!



**Herlinde Schneider,**  
Chairperson  
FamilyTies  
Foundation



**Andreas Podeswik,**  
Head of ISPA,  
Scientific  
Cooperation Partner

## Promotional Award 2012

### Prevention is better than curing!

Two further organisations with creative and outstanding Sibling projects who share the Promotional Award in the category "Trusted and interdisciplinary palliative care" are featured in detail in this issue.

## Outstanding practical examples

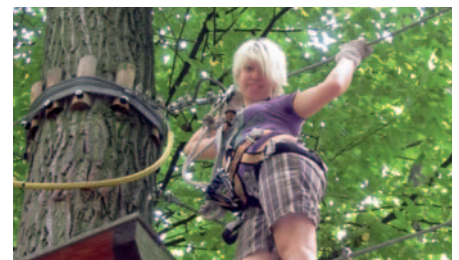


The Kinderhospiz Regenbogenland [Rainbow Land Children's Hospice] is like a colourful second home where they experience trust and security.

## A home for siblings

### The Rainbow Land Children's Hospice

The Rainbow Land Children's Hospice is a home for families with children facing a limited life expectancy because of an incurable illness or disability. It is the siblings of children suffering from a life-limiting disease in particular who are to be supported and cared for by giving them the recognition and help they need. The hospice has also developed a resource-oriented sibling programme with lots of experiential and recreational educational elements. In addition to a variety of monthly sibling get-togethers, the Rainbow Land Children's Hospice organises a "Siblings' Weekend" once a year, where the goals and content of the siblings concept can be discussed and reinforced.



### A word from the award-winner:

"Our 'secret' is that we focus entirely on the children's needs and put them centre-stage for that day. We listen to them attentively and concentrate on their resources. We take them as they are and give them our full and undivided attention."

*Hendrik Künzler,  
Rainbow Land Children's Hospice*



Foto: Fotolia/Seva Etchison



## Forum

### Cycling for FamilyTies

On 16th July, under the motto “get fit and do some good”, numerous employees from the Novartis Germany groups stood at the starting blocks to support Sibling Children on their way to work for the following 45 days. The principle: each time the participants cycled to and from work, they collected donation points to contribute towards organisations of siblings offers.



### Prevention: highly topical and innovative

At the 42nd Congress of Paediatrics and Adolescent Medicine on 22–24 June 2012 in Berlin, FamilyTies had the opportunity to approach new network partners and raise visitor awareness of the subject of sibling children. In keeping with the main theme of the congress - „New aspects of prevention in childhood and adolescence“ - the “LARES” questionnaire focuses on the early recognition of the particular strain placed on siblings. Anyone interested could not only take information away with them but also try out the new electronic version of LARES there and then.

**Try it out for yourself:** [www.stiftung-familienbande.de](http://www.stiftung-familienbande.de) (LARES)

From left to right: Tatjana Schindler, Irene von Drigalski, Novartis FamilyTies Foundation



### Special praise from the jury of the FamilyTies Promotional Award:

“In addition to regular external supervision and weekly team meetings, the children’s hospice is in constant contact with other institutions, such as out-patient children’s hospice services, hospitals and social outreach centres. This promotes the exchange of innovative ideas on the subject of siblings from a wide variety of areas: sibling work is, after all, team-work. Also, as part of the paediatric palliative care of siblings, parents are able to contact trained social workers at any time with their concerns. In the Rainbow Land Children’s Hospice, the siblings are provided with someone they can trust and talk to, and can find new friends and support within a community.”

### Key Information

#### Rainbow Land Children’s Hospice

**Founded:** 2004

**Target group:** Siblings of children suffering from a life-limiting disease

**Age:** 7–18 years of age

**Duration:** Every first Saturday in the month, approx. 10 a.m. to 5 p.m.

**Venue:** Various destinations

**Address:** Torfbruchstraße 25, 40625 Düsseldorf, Germany  
[www.kinderhospiz-regenbogenland.de](http://www.kinderhospiz-regenbogenland.de)

**E-Mail:** [info@kinderhospiz-regenbogenland.de](mailto:info@kinderhospiz-regenbogenland.de)

**Tel.:** 0211/6101950  
(Hendrik Künzler)

### Outstanding practical examples

## For improved self-confidence and quality of life

### The SisBroJekt – Children’s Palliative Care Centre, Datteln



Moods and feelings can be acknowledged and expressed creatively in familiar surroundings.

SisBroJekt is a programme for healthy siblings of children with severe chronic diseases, cancer or disabilities at the Children’s Palliative Care Centre of the Vestische Clinic for Children and Adolescents in Datteln.

On numerous siblings’ days and weekends, the team heading the project offers an extensive programme which is composed of creative, musical and sporting elements thematically tailored to sibling children.

The main objective of the SisBroJekt is the prevention of physical and psy-

chological adjustment problems and maintenance of physical and mental health. The activities are also intended to improve the quality of life and raise the self-esteem of the siblings and to provide relief for the whole family.

### Special praise from the jury of the FamilyTies Promotional Award:

“The SisBroJekt was initially only planned for five months but, due to its success and regular consultation with the children and parents, it has been continuously extended and further de-





## Key Information

### Children's Palliative Care Centre of the Vestische Clinic for Children and Adolescents in Datteln

**Founded:** 2006

**Target group:** Siblings of sick or disabled children

**Age/Anzahl:** years of age, up to 20 participants

**Duration:** Up to 10 group meetings a year (pre-school, children and youth group)

**Address:** Dr.-Friedrich-Steiner-Str. 5, 45711 Datteln, Germany  
[www.kinderklinik-datteln.de](http://www.kinderklinik-datteln.de)

**E-Mail:** [c.vonlochow@kinderklinik-datteln.de](mailto:c.vonlochow@kinderklinik-datteln.de)

**Tel.:** 02363/975758 (Christina von Lochow)

veloped since its scientific evaluation in 2006. The SisBrojekt is integrated into both the FamilyTies network and the Sibling Children network of Lower Saxony so that experiences can be shared and there can be networking on other projects. Further networking and opportunities for further cooperation are planned for the future. The siblings are able to exchange ideas among themselves or with the professional group leaders and get to know one another better, all in a safe, familiar environment. The positive experiences, so-

cial skills and greater self-confidence gained from the group experience are then translated into their daily lives."

#### A word from the award-winner:

"Exchanging experiences with other experts and close consultations with the sibling children and their families mean that the project can be tailored precisely to the needs of children and adolescents. In the SisBrojekt they are given a secure space for themselves where they are able to check out what they are capable of and gain new experience."

*Christina von Lochow, Children's Palliative Care Centre*

## The fast, modern form of early diagnosis

### "LARES Siblings" e-learning



9-year-old Emil is quiet and gets good grades at school but complains of headaches and non-specific abdominal pain. His sister Maria has trisomy 21. Emil's case is a practical example from the new "LARES Siblings" e-learning, which can be completed online as of now on the FamilyTies website. The LARES early detection questionnaire (LARES: gods of the household worshipped in ancient Rome) offers assistance in identifying the strain and the associated degree of suffering of siblings of children with a severe chronic illness or disability and, where possible, in providing the child with specific assistance.

A number of questions usually arise before LARES is used for the first time: When should the questionnaire be used? How do I address the issue with the family? How does the early diagnosis tool actually work? In order to answer these questions, FamilyTies has designed an e-learning program together with the ISPA which is not tied to a fixed place or time. This allows profession-

## From the world of science



als from the health and social service sector to use this modern form of continuing education to learn how to complete and evaluate the LARES form quickly and in their own way.

Users can move freely within the LARES modules. Following general explanations on siblings topics and on the LARES questionnaire, there are some practical examples, which give you the opportunity to try out the application of LARES in detail and to reflect upon its use. Additional networking and contact points as well as various links and downloads complete the program

[www.stiftung-familienbande.de/elearning/index.html](http://www.stiftung-familienbande.de/elearning/index.html)



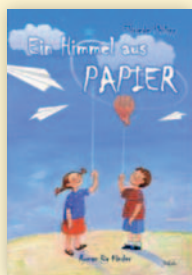
And how is Emil six months later? Now that he has taken part in a sibling programme with special anti-stress seminars Emil no longer has any headaches. He would also like to take part in programmes like these in the future.

## Reading and TV tips

### Ein Himmel aus PAPIER

[A sky out of paper]  
by Elfriede Philipp

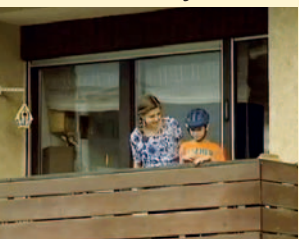
Friederike's best friend has moved away, and the other children do not much like to come to her home because Friederike has a brother who is different, in fact quite special. Sometimes she is ashamed of him, for instance, when he laughs louder than the others or says funny things. And mum always has to keep an eye on him. But then there is a secret pen friend whom she can always confide in completely. This exciting novel sensitively highlights the role of siblings of children with disabilities. (7-14 years)



## Siblings in the shadow

On 13 July 2012, ZDF Info broadcast a 30-minute feature "Geschwisterkinder – Leben in der zweiten Reihe" [Sibling children - life playing second fiddle]. It successfully provided an insight into the lives of the affected siblings and their families. The primary focus was particularly the work of Marlies Winkelheide, a graduate in social sciences, who has been developing activities for siblings for over 30 years. The documentary can

be viewed on  
<http://www.zdf.de/ZDFmediathek#/beitrag/video/1683486/Geschwisterkinder>



Stiftung  
**FamilienBande**  
Gemeinsam für Geschwister

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### We value your opinion!

Please tell us what you liked about the FamilyTies AKTUELL newsletter or what could be improved. If you do not wish to receive the newsletter, please drop us a line at [info@stiftung-familienbande.de](mailto:info@stiftung-familienbande.de)

## Latest news

### "There is a lot to do!"

Irene von Drigalski becomes managing director of the FamilyTies foundation



From October 1st 2012, as managing director of the Novartis Family Ties Foundation, Irene von Drigalski will be campaigning for continuing support for sibling children.

social service sector, supports the activities of FamilyTies in an advisory capacity. Among them is Prof. Ulrike Ravens-Sieberer MD of Hamburg University, who has acted as scientific adviser to the initiative from the outset.

Irene von Drigalski, who is to assume her position as managing director of the foundation as of 1 October 2012, also confirms that FamilyTies, in its new legal form as a foundation, has been put on a secure and sustainable footing. Her extensive experience in the field of project management and communications not only for industrial enterprises but also for social welfare bodies means that Irene von Drigalski is well aware of the need to network with partners from the business and academic worlds.

"It is good to know that the FamilyTies Foundation will continue to provide support for sibling children and their parents in the long term, because whomever you ask, virtually everyone knows at least one person from their own family, circle of friends or working environment who is affected. There is, therefore, an awful lot to do!"

## About the FamilyTies Foundation

The aim of the Novartis FamilyTies Foundation is to contribute to the promotion of health and prevention with the slogan "Help for Self-help". Information and education are one of the three main points of focus as the risk of stress in healthy siblings is often not acknowledged. As a result, more than 140 services for siblings are summarised in a database on the FamilyTies website. Visit FamilyTies on [www.stiftung-familienbande.de](http://www.stiftung-familienbande.de) or send us an e-mail: [info@stiftung-familienbande.de](mailto:info@stiftung-familienbande.de)



A date for  
your diary

## Symposium 2013

Please make a note of it today:

**15/16 March 2013**  
**Venue: Nuremberg**