

Working together for siblings



Foto: Fotolia/Sonya Etchison

Editorial

Ladies and gentlemen, dear friends of FamilyTies,

“Are there books for siblings of premature babies?” “Who can conduct sibling seminars?” These are just two of the many questions that are addressed to the FamilyTies Infoline every day – a telephone and email information service available to both professionals in the field and families. Isolde Stanczak (Institute for Social Medicine Augsburg – ISPA) – the voice of the Infoline – tells us about her experiences and impressions.

This issue focuses mainly on the third symposium of Working Together for Siblings, which was held in Nuremberg from 14 to 16 March 2013. You can read about the numerous talks and practice-oriented workshops as well as about the other highlights of the symposium, such as the panel discussion on inclusion, at www.stiftung-familienbande.de.

Just how important networking is for sibling projects is demonstrated by the Network for Siblings, which is made up of eight separate organisations that collaborate to ensure that sibling children receive consistent care. The Network for Siblings was the winner of the FamilyTies Promotional Award in the category “Networking” and describes its work in detail in this issue.

We hope you will enjoy reading this issue. Working together for siblings!



Mark Never,
Chairman of the Board Novartis FamilyTies Foundation



Irene von Drigalski,
Managing Director Novartis FamilyTies Foundation

Symposium 2013



There was much lively discussion both in the intervals ...

Strong and living life to the full

The 3rd symposium of Working Together for Siblings provided new ideas for promoting the life skills of siblings.

The main focus of this year’s third symposium of the Novartis FamilyTies Foundation held in Nuremberg from 14 to 16 March was finding ways of helping sibling children to become stronger individuals and develop their internal resources, so that they are happier with their lives. Over 120 experts from Germany and Austria attended the symposium.

Both academics and practitioners presented the results of their research and experience in seven plenary lectures and eight workshops. “We can’t give you anything – only the desire to learn and seek more” – this was the heading

of the talk, which was given by Marlies Winkelheide, Advisory Centre for the Sibling Children of the Support Group Bremen e.V, and which was addressed to both parents and sibling children. The practice-oriented workshops also attracted many participants. There was something for everyone, from “Philosophising with children” (Antje Schaaf, consultant attached to the Academy of Children Philosophising at the Educational Institute of Industry and Commerce in Bavaria e.V., Munich) to “Development of opportunities from the perspective of empowerment” (Volker Rinne, Network for the Care of Severely Disabled Children and Adolescents e.V., Medical University Hannover).

Five sibling children also represented sibling children at the symposium and spoke on their behalf. Tom, Pauline, Franziska, Christian and Simon from the Siblings Council in Bremen read out a memorandum in which they stated what they felt should be provided in support programmes for sibling children. “We want equality, recognition and respect, we want a framework to be set up for us, in which we can act and be heard!” – this was their message.



...and in the plenary lectures.

Forum



Gangnam style for sibling children

On 9 February, a Gangnam-style event for sibling children was the main feature of a meeting of the Round Table for Sibling Children Marburg. This was the first event organised for sibling children in Marburg. The goal is to make this event the first of a whole series of events for sibling children in Marburg. Even though only six of the 16 participants were sibling children, all the children and teenagers had a wonderful time. This event was sponsored by the Novartis employee fundraising campaign, Cycling for FamilyTies 2012. A second event is planned for September 2013, an invitation to a climbing garden in Marburg followed by a barbecue in the grounds of the Kerstin-Heim.

Our tip this issue: the feelings quartet card game

Played at any time just like any other card game, either at home with the family or at school, this lovingly illustrated card game provides an opportunity to discover through play how sibling children are feeling. The cards cover a wide range of feelings, such as joy, happiness, pride, sadness, disgust, or anger. In addition to the traditional quartet card game, the cards can also be used in other ways, such as for role-play, pantomime, question-and-answer games and much more. The card game is therefore very versatile. It is available through Amazon, at www.amazon.de.



In a panel discussion, affected siblings, parents and experts discussed the significance for sibling children of the planned introduction of inclusion at German schools in 2013. The FamilyTies Foundation had conducted an online survey on the issue beforehand in which 104 experts, parents and siblings took part. The conclusion of the survey was that inclusion is a social learning process, which will take many years and which, if implemented prop-

erly, will allow children to learn how to treat one another with respect by attending the same school. The politicians must be held to their word and teachers must receive proper training.

You can download the results of the survey and other documents from the symposium as pdf files at

www.stiftung-familienbande.de

FamilyTies Promotional Awards 2013



Four separate organisations were delighted to receive an award for their unique projects at this year's Promotional Award ceremony.

The 3rd FamilyTies Promotional Awards for outstanding projects supporting sibling children, with total prize money of 10,000 EUR, were presented to four separate organisations at an evening event. The winners in three differ-

ent categories were selected from a total of 18 entries by a jury headed by Prof. Ulrike Ravens-Sieberer, Associate Professor Dr Michael Kusch, and Dr Birgit Möller, with each of the winners receiving an award of 2,500 EUR. The winner in the category "Networking" is the Network for Siblings, which features in this issue.

A highlight of the evening was a reading from the novel "Three Words out of the Blue" by the author Maria Knissel. She was accompanied on the saxophone by Stephan Völker. The novel deals with disability through the eyes of a sibling child. It is based on the true story of the saxophonist Stephan Völker, whose elder brother, seven years his senior, was severely injured in a motorbike accident in 1977.

Go to www.stiftung-familienbande.de for further information about the winners.

Award winners 2013

In the category Innovation/First Project

- **Foundation for Family-oriented Aftercare Hamburg See YOU "CU"**
www.nachsorge-hamburg.de
- **Society for Mucopolysaccharidoses (MPS) e.V.**
www.mps-ev.de

In the category Parent Work

- **Federal Association for Children with Heart Disease e.V. (BVHK)**
www.bvhk.de

In the category Networking

- **Network for Siblings Achieving more together**
www.elternhilfe-leipzig.de



Maria Knissel und Stephan Völker

"A very moving story about two very different brothers."

Radio Hessen

Award winner of the FamilyTies Promotional Awards 2013 in the category "Networking"



Christoph Graf, Liebenau Foundation (far left) and Irene von Drigalski, Managing Director of the Novartis FamilyTies Foundation (far right) join in the delight of the proud winners: Tobias Schellenberg, Björn Schulz Foundation, Christa Engelhardt and Florian Schepper, Parental Support for Children with Cancer Leipzig e.V., and Corinna Neidhardt, Ray of Sunshine e.V. Dresden (centre of picture, from left to right)



Now it's MY turn!
NETWORK FOR SIBLINGS

A word from the award winner

"In supporting sibling children and developing new models to achieve this, it is extremely important that these models are evaluated and documented scientifically. This ensures their further improvement and provides proof of their sustainability. This is the only way to establish comparable support for all sibling children throughout Germany. Winning a 2013 FamilyTies Promotional Award is both an incentive and an obligation for the Network to continue to provide the best possible support for sibling children and in a way that always meets their needs."

Florian Schepper, Parental Support for Children with Cancer Leipzig e.V.

Now it's My turn!

Network for Siblings. Achieving more together

The Network for Siblings is a network project that seeks to ensure the provision of standard care for the siblings of severely ill children in Saxony, Thuringia, Saxony-Anhalt, and Berlin. Eight separate partner organisations collaborate in the network:

- Parental Support for Children with Cancer Leipzig e.V.
- Parent Initiative for Children with Leukaemia and Tumours Suhl/Erfurt e.V.
- Ray of Sunshine e.V. Dresden – support group for children and teenagers with cancer
- Society for the Support of Children with Cancer Halle (Saale) e.V.
- Parent Initiative for Children with Cancer Jena e.V.
- Björn Schulz Foundation Berlin
- Parents' Association for Children with Cancer Chemnitz e.V.
- Magdeburg Support Group for Children with Cancer e.V.

Scientific modules are jointly developed and evaluated, in order to achieve defined goals and the development of a common standard for the support of siblings. These modules minimise development risks and help support the

mental health of sibling children by seeking to prevent the development of psychological disorders. The breadth of the network allows sibling projects to be established and developed further as regards contents on a sound scientific basis. The primary aim of the network is to establish long-term needs-oriented support for sibling children in the area.

The jury of the FamilyTies Promotional Awards had the following special words of praise:

"The organisation Parental Support for Children with Cancer Leipzig e.V. was already awarded a FamilyTies Promotional Award on 8 February 2011 in



Network meeting in Leipzig: Thore Spilger (ISPA) presented a documentation plan, which allows, for the first time the key aspects of the support programmes available for sibling children to be recorded.

recognition of its particularly outstanding and innovative sibling projects. It was on the evening of the Award ceremony that the future partners in the Network first got to know one another and discovered that they shared many common goals. This led to the establishment of the network. The Network consists of eight organisations involved in cancer support and also collaborates with the Institute for Social Medicine in Paediatrics Augsburg (ISPA) and with the Hannover Siblings Network. What is particularly outstanding about the Network is the link to a prevention concept for sibling children in a modular format. This concept is developed, supported and evaluated on a scientific basis. So far unique in Germany – various psychosocial modules are established, which minimise development risks and help support the mental health of sibling children by seeking to prevent the development of psychological disorders."

Key information

Network for Siblings Achieving more together

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Recommended books

by Marlies Winkelheide

Planet Willi by Birte Müller



Through her descriptions of various worlds, the author sensitively presents the life of Willi, a child with a disability, and his encounters with his whole family and the general public. In this colourfully illustrated picture book, she creates communication bridges for a better understanding and good relationships within and outside of the family. Birte Müller knows what she is writing about as she is the mother of a child with trisomy 21 and a younger sibling child. Every library should have this book on its shelves.

I don't love you, but I wish I once could

by Tessa Korber

The book is an uncompromising description of life with an autistic child seen through the eyes of his mother. Tessa Korber is writing her own story and, in her

book, she confronts all the challenges life with an autistic child presents for all the members of the family. She also examines the point of view of her elder son, who has his own very special way of dealing with his brother's condition and the changes in the family. The book is well worth reading on many accounts.

Latest

FamilyTies Infoline – questions and yet more questions!



Carrying out research and providing information are just as much a part of the daily routine as having personal conversations about the situation of sibling children and their families. Sometimes there are no specific concerns and the person is “just” calling for a chat to find some relief and fresh hope.



Isolde Stanczak (education-
alist, case manager, and
coach), ISPA

The FamilyTies Infoline has been available as a service to professionals and affected families since 2010. In 2012, Ms Isolde Stanczak, employee of the Institute for Social Medicine in Paediatrics Augsburg (ISPA), a non-profit organisation, provided a total of 493 items of information by telephone and email. Virtually half of all the enquiries came from specialists in psychosociology.

Most of those calling are seeking help in their search for suitable support for siblings and their families. A case in point is Ms U: working at an advisory centre and, pressed for time, she was unable to find appropriate support for a sibling child. The family concerned had been coping quite well with their multiply and severely disabled daughter until the father suffered a stroke. Ms U had been able to organise all kinds of help for the long-suffering family, but the twelve-year-old son was becoming increasingly withdrawn and looked, in her own words, “infinitely sad”. This is just the kind of situation in which the Infoline can provide support. Psychological counselling was initiated and links to a mentoring programme and to local support programmes for sibling children were provided.

In addition to the search for suitable help for sibling children and their relatives, there were also many enquiries from professionals in the field about the practical application of LARES (questionnaire for the early detection of the particular burden on the siblings of severely ill or disabled children), further

training, the appropriate methodology for support programmes for sibling children (“Do you know a game relating to the topic of relationships between siblings?”) and about books (“Are there books for siblings of premature babies?”) as well as enquiries from those looking for someone to give a talk (“We need someone who can lead a discussion at a parent’s meeting on the topic of siblings.”).

The enquiries came mainly from areas in Germany that (still) do not have sibling support programmes. It is usually the mothers who are very worried about the well being of the siblings, who describe the stress that the siblings are under and how they struggle to cope with all the challenges of every day life and who seek help. One example was a single mother who had to completely reorganise her life when she had to move because of her job, and had no family or friends to help her. She rang the Infoline in desperation when her five-year-old daughter with trisomy 21 had to have heart surgery. There was no one to look after the ten-year-old brother. With the help of the Infoline, she was soon able to find the necessary contacts and support.

Give us a call! The FamilyTies Infoline is available to both professionals in the field and to families and can be contacted directly on +49 (0)1805 322633 (0.14 EUR a minute German landline, max. 0.42 EUR a minute on a mobile network). Or send us an email at info.stiftung-familienbande.de.

Interview in issue 02/2013

In the next issue, Dr Assia Kemih, specialist in general medicine, will be talking in an interview about her experiences as the mother of a severely disabled son and an older daughter.



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