

Working together for siblings

Editorial

Ladies and gentlemen,
Dear Friends of FamilyTies,

It is exactly one year since we sent out the first edition of Family Ties LATEST to a group of around 250 experts and institutions focusing on sibling children. Since then, the number of interested parties has more than doubled to over 600 recipients, with new ones joining us every day. We would like to take this opportunity to thank all our readers for their loyalty. And we're also asking you to tell us about your likes and dislikes and which topics you want to learn more about. Just send us an e-mail at info@stiftung-familienbande.de.

This issue's main topic is the symposium "Working Together for Siblings", which took place in Nuremberg in mid-March. Those of you who attended the conference will find impressions of the event summarised in this issue, including the highlight of that festive evening, the honouring of Marlies Winkelheide for her life's work.

In this issue and the next, we again want to present the winners of the 2nd Family Ties Promotional Award, together with their successful strategies in supporting siblings – starting with the Welfare Association Bavaria (VdK).

We hope you enjoy reading this edition of Family Ties LATEST. Working Together for Siblings!



Herlinde Schneider,
Chairperson of the
Family Ties Foundation



Andreas Podeswik,
Head of the Institute
for Social Medicine in
Paediatrics, Augsburg
(ISPA), Scientific
cooperation partner

Symposium 2012

Intensive Networking

The 2nd Symposium "Working Together for Siblings – points of access, issues and approaches in working with sibling children" once again attracted well over 100 experts from Germany, Austria and Switzerland.



In line with the participants' wishes, this year's symposium offered plenty of scope for lively discussions and an intensive exchange of ideas.

"A regular and intensive exchange within a growing network is essential in order to gain an understanding of siblings' needs and to offer appropriate support." These were the opening words of Herlinde Schneider, Chairperson of the Family Ties Foundation, at the second symposium, which took place in Nuremberg on 16 and 17 March.

At the request of the participants and experts, the main focus lay on joint discussions and specific project work. Twelve speakers gave an insight into their work and compared notes with the participants during practically oriented workshops.

Offering a scientific perspective, Prof. Klaus Fröhlich-Gildhoff, from the Centre for Child and Youth Research at the Protestant University of Applied Sciences, Freiburg, illustrated the topic of resilience, i.e. the mental robustness of children in particularly stressful situations: "Good problem-solving skills and the ability to self-regulate play a key role in overcoming the challenges to

which a sibling is exposed", said Prof. Fröhlich-Gildhoff.

Melanie Jagla from the University of Flensburg focused on various prevention strategies and a specific programme to provide psychological support and to promote life skills in siblings. As she pointed out: "A chronic disease or disability affects all aspects of family life and so support should be forthcoming at an early stage."

Prof. Naguib Khouzam, an activist for the disabled and head of the Caritas Centre SETI (Support Education Training for Inclusion) in Egypt (see more on page 4), provided an international insight. This allowed participants to benefit from his practical knowledge and integrate what they had learnt into their own work: Working Together for Siblings!

The lectures, abstracts and workshop documentation from the symposium are available for download as PDFs at www.stiftung-familienbande.de



Foto: Fotolia/Sonya Etchison

Forum



Family Ties Creative Action

What's it like living with a brother or sister who has Down's syndrome? This question was aimed at all siblings who wanted to share with Family Ties not just their happy experiences, but also the funny, sad, exciting and annoying ones. As a highlight, the many essays, pictures and poems submitted were presented by Family Ties at the Down's Syndrome Sports Festival in Frankfurt on 5 May 2012 and published at www.stiftung-familienbande.de

A Future for Forgotten Children

"We mustn't forget the special needs of healthy siblings. Let us continue to focus on their future and the well-being of all children!" said Prof. Hubertus von Voß, Federal Chairman of the registered society "The Children's Network for Children, Adolescents and (Young) Adults with Chronic Diseases and Disabilities". "A Future for Forgotten Children" was the slogan of the 2nd Berlin Appeal 2012, which formed part of the Jubilee Symposium "20 Years of the Children's Network", which took place in the Charité University Medical Centre in Berlin from 22–24 March. The aim of the Appeal is to raise political and social awareness of the issue and of the needs of affected children and their families.

Find out more at www.kindernetzwerk.de



2nd FamilyTies Promotional Award

Award-winning Commitment

The 2nd Family Ties Promotional Awards for outstanding projects supporting sibling children were awarded as part of this year's symposium, with a total sum of 10,000 euros being awarded.



Honouring Marlies Winkelheide for 30 years of sibling support: In Bremen, the sibling council's apple tree was planted in the garden of the Niels Stensen House, which lies on the way to the Janusz-Korczak memorial, where work with siblings first began 30 years ago.

Under the direction of Prof. Ravens-Sieberer, Dr Kusch and Dr Möller, the scientific advisory board selected and awarded prizes to six winners in four categories from the 25 entries (with the prizes in two categories being shared between two winners). The overall winner across all categories was the Welfare Association of the VdK Bavaria, Munich, which is featured in this edition. A particularly pleasant surprise was in store for Marlies Winkelheide from the registered society Lebenshilfe in Bremen, who has been supporting affected siblings and their families for 30 years. As a symbolic gift in honour of her life's work, Family Ties presented her with an apple tree, which "will bear fruit in the future, just as her work for sibling children has done", as Herlinde Schneider of Family Ties explained on presenting the award.

Award Winners in 2012

In the category "Sustainable support for siblings of children with disabilities and impairments" and 1st place across all categories:

- Social Academy – Youth and Family, Welfare Association of the VdK Bavaria, Munich, www.vdk.de

In the category "Innovation in paediatric oncology":

- Anna – Support for children with cancer, Filderstadt (registered society), www.annaverein.de

In the category "Trusted and interdisciplinary palliative care":

- Kinderhospiz Regenbogenland [Rainbow Land Children's Hospice], Düsseldorf, www.kinderhospiz-regenbogenland.de
- SisBroJekt – Children's Palliative Care Centre, Datteln, www.kinderklinik-datteln.de

In the category "Sensitisation or prevention in chronic diseases"

- BUNTER KREIS [MULTICOLOURED CIRCLE] in the Aachen region (registered society) www.bunterkreis-aachen.de
- SupaKids – DRK-Schwesternschaft [German Red Cross Sisterhood] Hamburg (registered society), www.supakids.de



For further information about the award winners, visit www.stiftung-familienbande.de

1st place across all categories goes to the Social Academy – Youth and Family, Welfare Association of the VdK Bavaria



Proud winners (from left to right): Phil Hubbe (cartoonist), Andreas Podeswik (ISPA), Tina Gerlach and Eberhard Grünzinger (VdK Bavaria). Celebrating with them: Christoph Gräf (Liebenau Foundation), Herlinde Schneider (Novartis)

have as a sibling?’ and transforming the answers onto paper in a creative and individual style.“

A word of advice from the award winner:

“A particularly important and fundamental aspect of the work is the consistency and reliability of the activities for siblings. The activities offered must also be available during years that see less interest and fewer applications. What matters is not a maximum number of participants but rather the individual support siblings receive. Even a small sibling group is therefore just as educationally demanding and equally well worthwhile organising.”



A holiday on the dream island of “Make a Wish”

As part of the annual symposium of the German Tuberous Sclerosis Association (registered society), siblings between 8 and 15 years of age were carried off to “Make A Wish Island” under the guidance of Eberhard Grünzinger. A very special, almost magical place, where the siblings of children suffering from the incurable disease tuberous sclerosis were allowed to dream about all possibilities and impossibilities. This year’s excursion was sponsored by the LORENZ Foundation in Frankfurt.

All-Round Care for Sibling Children

For about 30 years, the VdK Social Academy has been organising family seminars and holiday activities for children and adolescents with and without disabilities.

In addition to the varied supportive opportunities offered to affected families, the Social Academy also provides a special annual activity programme for sibling children. Educational seminar modules are also provided to help siblings identify and deal with the opportunities and challenges of their particular situation.

One of the goals of the VdK Social Academy is to empower sibling children by offering them a range of options, to show them that they are not alone in their situation and to give them the attention they need to allow them to develop freely.

Special praise from the jury of the Family Ties Promotional Award:

“We are particularly impressed by the untiring commitment to affected families that the VdK Social Academy shows throughout the year. Children and their families can benefit from a wide range of organised activities and find themselves right at the heart of events. What also sets the VdK Social Academy apart is its large catchment area, broad target group and the many years of networking and lobbying on behalf of sib-

lings. The sibling children’s activity programme has been in existence since 1997, its events offering a wide range of educational activities, such as sport, self-defence or circus training, and the programme is constantly updated to meet the needs and wishes of the children and adolescents. A good example is last year’s comic seminar with cartoonist Phil Hubbe, which proved highly popular with the children and which will therefore be continued in 2012. The artist turned the weak into heroes and siblings into superstars by asking the question ‘What unique experiences do you



With his drawings, Phil Hubbe transformed the weak into heroes and siblings into superstars.

Basic Information

Social Academy – Youth and Family, Welfare Association of the VdK Bavaria

Founded: 1946

Target group: Siblings of disabled or chronically ill children

Ages: 8–16 years

Duration: Sibling children’s activity programme – once a year. Dates for 2012: 02.–09.09. (Steingaden)

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Tina Gerlach/Eberhard Grünzinger

Siblings in the Media

"Look after him!"

Die ZEIT (newspaper), 1 March 2012



An increasing number of media are showing interest in the issue of sibling children and are helping to raise public awareness of their concerns. In his ar-

article "Look after him! Siblings of ill or disabled children often carry a heavy burden. Now they can receive specialised help", Martin Spiewak, science editor of "Die ZEIT", introduces sibling children who are or have been affected and outlines options for appropriate care. For further details visit www.stiftung-familienbande.de.

Fun with Painting and Reading

"Karline Schlenkerbein und der Tüpfenteufel" ["Karline Longlegs and the Speckled Devil"] by Steffi Hahn

In her 3-volume painting adventure, and writing under her pen name of "Hanne Hatschi", the author Steffi Hahn tells the story of Karline Longlegs. At night, Karline Longlegs dreams her way into the kingdom in the clouds, where she has exciting adventures. The author uses the third part of her tale to raise awareness in a child-oriented way of the problems facing siblings of ill and disabled children. For further details go to www.karline-schlenkerbein.de.



FamilyTies

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We value your opinion

Please tell us what you liked about Family Ties LATEST or what could be improved. If you don't wish to receive the newsletter, please email us at info@initiative-familienbande.de

International Exchange



Sibling Support in Egypt

"Working together for siblings" is a central issue that is receiving growing attention, and not just in Germany. In other countries too, there has been help and support for affected siblings for many years. One example is the work of the Egyptian activist for the disabled, Prof. Naguib Khouzam, who has been running the Caritas Centre SETI (Support Education Training for Inclusion) since 1986.

International Exchange

The 62-year-old professor travelled to Germany to encourage an international exchange of ideas on the issue of siblings. His first stop was Freiburg, where the German Caritas Association awarded him the Lorenz Werthmann Medal for outstanding achievements in work with the disabled. He then spoke at this year's Family Ties symposium in Nuremberg on 16/17 March about the innovative educational approaches and fundamental ideas of the SETI Centre.

Educating against prejudice

In Egypt and throughout the Middle East, having a mentally disabled child often still carries a social stigma. If one family member is affected, the entire family has to face prejudice. Families at the poorer levels of the population are particularly likely to suffer social exclusion as a result due to the limited educational opportunities. Only a few non-governmental organisations, such as the Caritas Centre SETI, foster and support disabled people and their families. In line with the slogan "Helping people to help themselves", the institution's goal is to build a support system that takes the complete environment of the affected person into account. In keep-

ing with this, SETI has developed teaching plans and training programmes that target not only parents but also specialists and caregivers in the disabled sector.

Active for and with siblings

Since 1998, the healthy siblings of disabled children have been receiving special attention, thanks to programmes developed specifically for them. SETI has set itself the task of improving the children's knowledge of their sibling's disability, to strengthen both the bond between the siblings and the healthy child's own self-esteem as an individual person and to provide a reassuring space for expressing feelings. The wide-ranging programme aims to provide relief and respite for the whole family. In addition to various recreational activities, such as holiday camps, excursions and art projects, it is the communal activities that do most to create close mutual trust and a strong bond within the group. These activities include writing magazines, producing a film or simply enjoying being cosily together during a meal or a storytelling session.



For further information, visit www.caritas-international.de

Prof. Naguib Khouzam's lecture is available for download as a PDF from www.stiftung-familienbande.de