

Working together for siblings



The SuSi (Supporting Siblings) prevention course

Sibling support made easy

The first manual to help ensure the standardised implementation of a sibling children support service – a service that is now eligible for reimbursement under article 20 of the 5th German Social Code Book (SGB V).



The SuSi (Supporting Siblings) prevention course developed by the Institute of Social Medicine in Paediatrics Augsburg (ISPA) and the University of Flensburg is the first group sup-

port service that is now recognised by supraregional statutory health insurance providers. SuSi provides training in life skills for the siblings of chronically ill, severely ill and/or disabled children. The training helps them manage stress and acquire social skills and promotes their self-esteem. The 6 modules teach sibling children between the ages of 8 and 12 the necessary skills to cope with their particular situation.

The SuSi manual is published by the Bundesverband Bunter Kreis. The course will be distributed and reimbursed in future via this federal association.

Manual now available

SuSi was funded in 2012/2013 by the Novartis FamilyTies Foundation. A manual has now been developed to ensure standardised distribution. This manual is now available (see below). It summarises the principles underpinning the development of support services for sibling children and describes the conception, methods of assessment and aims of the SuSi prevention course. The instructions on how to conduct the 6 modules and the attached teaching materials provide practical assistance in setting up and running the course.

For more information, contact:

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To order, contact:

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Editorial

Ladies and Gentlemen, dear Friends of FamilyTies,

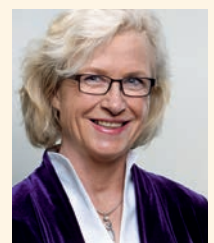
Sibling children should grow up healthy and develop to their fullest potential – not always an easy task. The new manual for the SuSi (Supporting Siblings) prevention course, developed by the Institute of Social Medicine in Paediatrics Augsburg (ISPA), helps make this task easier by providing practical advice to help ensure the standardised implementation of a sibling support service.

The 4th FamilyTies Promotional Awards for outstanding projects in sibling children support were presented at the Sibling Children Network symposium in Wolfsburg on 26 April 2014. There were three winners (and also a special mention) this year. We will be presenting these projects to you in this and subsequent issues.

The first FamilyTies Foundation Siblings Olympics were also held this year at the 2014 German Down's Sports Festival. They were attended by the new Hexal CEO, Sandrine Piret-Gerard, who was so enthusiastic about what she saw that she stayed the whole day and did not fly back for other appointments at mid-day as planned. As always, 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

The first sibling children support service eligible for reimbursement across Germany!

SuSi is the first course for sibling children that is recognised by the statutory health insurance providers under article 20 of the 5th German Social Code Book (SGB V) due to the standardised manner in which it is carried out, assessed and documented, but also because it meets the requirements of service provider.



Welcoming all partners and the 150 guests at the symposium on behalf of the many supporters of the Sibling Children Network of Lower Saxony, were (from left to right): Jörg Röhmann, Secretary of State in the Ministry of Social Affairs, Women, Family, Health and Integration of Lower Saxony; Martina Flamme-Jasper, Head of Communications at phaeno GmbH Wolfsburg; Dr Wolfgang Eberl, specialist in paediatric and adolescent medicine, senior consultant in paediatric haematology and oncology at the hospital of Braunschweig, chair of the Network for the Care of Chronically Children and Adolescents e.V.; and Gerd-Ulrich Hartmann, Managing Director of the Kroschke Children's Foundation.

4th FamilyTies Promotional Awards

3 first-time sibling children projects honoured with a promotional award

The 4th FamilyTies Promotional Awards for outstanding projects in sibling children support were presented during this year's symposium of the Sibling Children Network held in Wolfsburg on 26 April 2014. The awards are worth a total of € 5,000 to the winners.

150 people attended the symposium under the heading "Reducing the strain on families on a needs-basis through the provision of support for sibling children – Reviews, Insights, and Prospects", which was held at the Theatre of Science of the phaeno World of Experience in Wolfsburg. The symposium was organised by the State of Lower Saxony and the Sibling Children Network of Lower Saxony. In his opening address, the Secretary of State of Lower Saxony, Jörg Röhmann, stressed the importance of reducing the strain on families with severely ill children by enabling sibling children to become stronger and cope better through prevention. The highlight of the day was the presentation of the FamilyTies Promotional Awards jointly given by the FamilyTies Foundation and the Sibling Children Network to support new sibling children projects.

Entries were sought from first-time sibling children projects that would not otherwise have come to fruition without initial support. Of the 25 entries received, three were selected as winners by a panel of experts comprising Prof. Dr. med. Dirk Reinhardt (Hanover School of Medicine), Andreas Podeswik (Institute of Social Medicine in Paediatrics Augsburg) and Christoph Gräf (Liebenau Foundation). The DRK Children's Hospital in Siegen received an award to the value of € 2,000 for promoting early contact between siblings and their prematurely born brothers and sisters

(further details on the following page). Mittendrin Hannover e.V. was awarded €1,500 for its inclusive garden project. The Wupperlebnis e.V. was the third award winner and the delighted recipient of € 1500 for its "Über(s)Leben" training [word play which cannot be reproduced in English meaning survival training/training about life]. The panel also had particular words of praise for the online advice service for adolescents provided by the outpatient hospice service/children's hospice service in Oldenburg. However, as this was not a first-time project and specific sibling support was only one aspect of it, it was not eligible for prize money. You can find out more about the FamilyTies Promotional Award Winners 2014 in this and subsequent issues.

The award winners at a glance Category: Innovation/ First-time project



From top to bottom:

DRK-Kinderklinik Siegen gGmbH
[www.drk-kinderklinik.de/
perinatal-zentrum/was-wir-machen](http://www.drk-kinderklinik.de/perinatal-zentrum/was-wir-machen)

Mittendrin Hannover e.V.
www.mittendrin-hannover.de

Wupperlebnis e.V.
www.wupperlebnis.de

**Special mention by the panel
Hospizdienst/Kinderhospizdienst
in Oldenburg**
www.da-sein.de



Takes part every year – Bobby Brederlow in the relay race

Siblings Olympics at the 2014 Down's Sports Festival

More than 2,500 visitors from all around Germany, including 566 competitors, attended the 12th Down's Sports Festival in Frankfurt-Kalbach on 17 May 2014. The FamilyTies Foundation was once again involved, but this year for the first time with the organisation of a Siblings Olympics. Over 300 families took part in the programme of events, including knocking down cans, an obstacle course, basketball shooting and football target goal shooting. The general feeling was that the Siblings Olympics were a welcome addition to the Down's Sports Festival. Particular highlights were a drum workshop for pairs of siblings and the hourly relay race, in which the actor and Bambi award winner, Bobby Brederlow, also took part with his brother Gerd.

2014 FamilyTies Promotional Award Winner

There from the very beginning

At the prematurity and neonatal intensive care unit of the DRK Children's Hospital in Siegen, it is not only the tiny patients who are the centre of attention but also, very recently, their siblings.



Tiny premature babies need a lot of particularly close contact and affection – from their siblings too.

A premature birth brings joy but also puts all those concerned under great strain. As Petra Nick, Head of Nursing in the Perinatal Centre (level 1) observes, the parents and the sibling children often find being separated from the baby so soon after birth and all the tubing everywhere very unsettling and so the routine manner in which the staff go about their work helps put them at ease. Her unit provides care for more than 400 premature and newborn babies every year, including very tiny babies weighing less than 500 grams.

Encouraging contact between sibling children and premature babies

Petra explains that in these unusual circumstances it is especially important to attempt to create a less alienating environment despite the intensive nature of the care being provided. The unit attaches great importance to ensuring that not only the parents but also the sibling children have contact with the tiny patients from the very beginning. "Involving the sibling children lessens the strain on the whole family", comments Petra. It is therefore important to explain to them why their new brother or sister is receiving so much attention and they as the older children are at the moment receiving less. Sibling children were previously denied contact with premature babies still receiving care at the hospital. The hospital is now seeking to change this. The unit received a 2014 FamilyTies Promotional Award for the sibling support service it now provides in "integrating sibling children in the Perinatal Centre & in the Intensive Care Unit & Ward 1". In giving the award, the panel were acknowledging that the early involvement of young sibling children would give rise to

new knowledge and that this was in tune with the preventive thinking underpinning working with sibling children.

Consideration of the individual circumstances is the key to success in working with sibling children

In Petra Nick's view, it is especially important that all concerned are open in their dealings with one another. The staff's understanding of the particular circumstances is the key to the success of the work they do. There is no standard way of going about things but each family and their circumstances have to be considered individually. Great importance is attached to the close involvement of parents and other relatives such as siblings in other areas of the hospital as well. For example, at the "Children Island" on an intensive care ward that is homelike in character for children and adolescents requiring permanent ventilation. The purpose of the homelike character of the ward is to provide care in a familiar environment even in acute cases of illness.



A "Children Island" patient requiring permanent ventilation and Department Head, Dr. Rainer Blickheuser

Key information

Founded: 1918
Patients: Children and adolescents aged 0-18
Address:
DRK-Kinderklinik Siegen gGmbH
Wellersbergstraße 60
57072 Siegen
Tel: +49 (0)271 / 23 45 - 0
Fax: +49 (0)271 / 2 19 55
Email: info@drk-kinderklinik.de
www.drk-kinderklinik.de



"Still a lot more planned": Aktion Mensch funds inclusion projects at local level.

"Still a lot more planned" is the new Aktion Mensch funding campaign launched at the start of the organisation's 50th anniversary. The organisation provides funding of up to € 5,000 per project for small local projects that make a specific contribution to implementing inclusion in our society. This could take the form of a children's cookery course, a drama project involving the able and the disabled, an inclusive sports project or a joint summer fete, for example. The new funding initiative is aimed in particular at organisations and associations that have so far not been affected by the issue of inclusion but which would like to take the first step along this path. For more information about this funding initiative, go to www.aktion-mensch.de/50jahre/foerderung

Survey on the state of care provision for families with chronically ill and disabled children in the Kinder Spezial magazine

The new issue of the Kinder Spezial magazine is out! The issue focuses on a large survey on the state of care provision in Germany for families with chronically ill and disabled children. The survey was carried

out by the Federal Association of the AOK, scientists from the University of Hamburg, the Children Network and the 2,000 parents and parent support assistants. The next issue, supported by the FamilyTies Foundation, will focus on the subject of sibling children. For more information and to order, go to www.kindernetzwerk.de/zeitschrift-kinder-spezial-des-kindernetzwerks.html



Recommended books

12 things I must do before the end of the world

Von Björn Sortland

There is 13 years old and convinced that the end of the world is nigh. Not surprisingly as her circumstances are anything but easy: her parents want a divorce, her disabled sister is demanding, and the boy she has fallen in love with is a bit dense. She has drawn up a list of 12 things she must definitely do before it all ends... An unusual story about the problems of a pubescent girl and at the same time a serious but light-hearted look at the fundamental questions of life. A book not just for young people but also for parents who want to understand the emotions of their growing children.

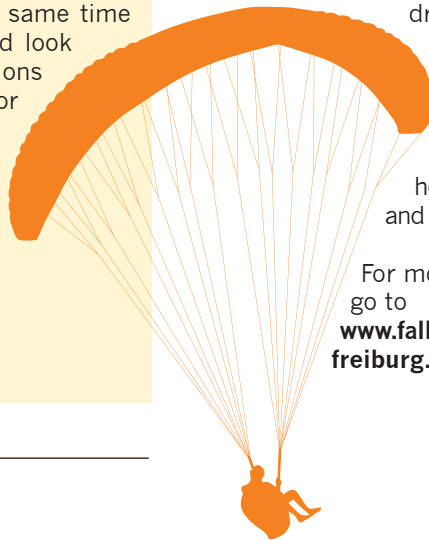


Parachutists in aid of FamilyTies

About €1,000 raised at a charity event in Freiburg!

To celebrate the 50th anniversary of the Breisgauverein für Fallschirmsport e.V. Freiburg (BVF), the sky divers came up with something really quite unusual: a charity event in aid of the FamilyTies Foundation. The parachutists organised aerial tours and tandem jumps, with the proceeds benefiting the FamilyTies Foundation. Together with the money from catering, a total of about €1,000 was raised in aid of the FamilyTies Foundation over the weekend of 17/18 May 2014. According to Helmut Lang-Dahlke, the chair of BVF, they chose the FamilyTies Foundation because parachutists feel, just like sibling children, that they live in the shadow of others, but in their case in that of the more powerful and higher-profile multi- and single-engine pilots.

For more information, go to www.fallschirmsport-freiburg.de



The FamilyTies Foundation was there with a stand



On the BVF site in Freiburg



Representing the FamilyTies Foundation at the event: Uta Seewaldt from Novartis (far left) with Helmut Lang-Dahlke (3rd from left), chair of the BVF, in front of the FamilyTies stand



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FamilienBande
Gemeinsam für Geschwister

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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 do not wish to receive the newsletter, please email us at info@stiftung-familienbande.de



FamilyTies attended the community health conference in Düsseldorf on 7 May 2014. As Prof. Dr. med. Andreas Meyer-Falcke, Health and Safety Officer for the state capital of Düsseldorf and now patron of the FamilyTies Foundation observed, "Joining community networks is important to ensure that contact can be made with affected families in the area. The city of Düsseldorf is keen to support the FamilyTies Foundation in ensuring that organisations based in Düsseldorf register in the online sibling support database."

Supported by