

Working together for siblings



Editorial

Ladies and gentlemen,
dear friends of FamilyTies,

“Working together for siblings” – that has been the guiding philosophy of FamilyTies from the very outset and is no less true today. Our mission has remained the same: to enable the siblings of chronically and severely ill or disabled children and adolescents to grow up healthy and to freely develop as normal, healthy individuals and to ensure that each sibling child can find suitable and high quality support when required. This is our vision and goal, which we will also jointly realise with your help in 2014.

A fitting example are four pilot projects being conducted by organisations in Berlin, Nuremberg, Marburg and the Southern Black Forest that have set themselves the task of exchanging knowledge and experience and networking with other organisations in their area. In this issue, we will shed more light on the various creative ways in which these projects are being realised.

The joint commitment of four organisations working together also made possible a very special day for very special families, the Sibling Time Action Day at the Ravensburger Spiel-land Theme Park. The SeeYou Foundation, which was a winner of a FamilyTies promotional award in 2013, will also show what makes its first project for sibling children so special.

We wish you a healthy and happy New Year 2014 and look forward to together further developing our commitment to sibling children.



Mark Never,
Vorstand (Vors.)
Novartis Stiftung
FamilienBande



Irene von Drigalski,
Geschäftsführerin
Novartis Stiftung
FamilienBande

Four pilot projects – four different approaches

The variety and creativity shown in the new programmes for sibling children are impressive

Establishing networks and exchanging experience and knowledge are key aspects of the work of FamilyTies. This is the thinking behind the launch by FamilyTies of pilot projects in four different areas – in Berlin, Nuremberg, Marburg, and in Wehr in the Southern Black Forest. All four projects are benefiting at start-up from the donations the employees of Novartis companies collected over Christmas or from in-house fund-raising campaigns such as “Cycling to Work for FamilyTies”. All four projects have been assigned the same task: to establish networks and develop a programme of support for sibling children in their area.



It is the job of those in charge of the projects to find out whether any or what type of support is available in their area, to develop ways of meaningfully working together to provide support and to determine what other partners could be usefully involved in setting up and organising this support. The experience gained will be collated by FamilyTies with a view to using it later to help other organisations develop their own programmes of support for sibling children. Each project is adopting a different approach, but they all have one thing in common – “round table discussions”.

Kindergesundheitshaus (Children’s Health Centre) in Berlin-Neukölln: three dates for siblings already set

The Kindergesundheitshaus e.V. met with the Berliner Arbeitsgemeinschaft Geschwisterkinder (Berlin Working Group for Sibling Children) at the Mother-and-Child Centre at the Vivantes Hospital in Neukölln and together spoke with representatives from the Neukölln Department for the Disabled. The discussions also involved the so-



Welcoming the launch of a sibling children project for the future support of sibling children in Berlin (from right to left): Johannes Singhammer, (Member and Vice-President of the German Federal Parliament), Mark Never (Chairman of the Novartis FamilyTies Foundation), Dr Hildegard Rossi (Kindergesundheitshaus Coordinator), Prof. Dr. Rainer Ross, (Senior Physician of the Paediatric Department of the Vivantes Hospital), Irene von Drigalski (Managing Director of the Novartis FamilyTies Foundation).

cial paediatric Diagnostic and Treatment Centre (DBZ Neukölln) at the same premises. The outcome of these discussions was the establishment of the Sibling Children Project – Work- →

Forum

New Infoline number



The FamilyTies Infoline now has a new telephone number. The service is free of charge to those paying a flat rate for their telephone calls;

otherwise the standard German landline rates apply. Family and friends of sibling children, doctors, and professionals working with sibling children can receive advice from experts, who will respond directly to questions about possible help and existing support for sibling children.

Tel. 07762 8199000*

You are also welcome to send your enquiry by email to info@stiftung-familienbande.de

** This landline number replaces the former telephone number, 01 805 322633. If you dial the old number, you will be automatically transferred to the new landline number.*

Invitation to the Sibling Children Symposium April 2014

Our collaborative partner, The Sibling Children Network, cordially invites you to its 2nd Symposium to be held at the interactive Phaeno Science Centre in Wolfsburg on Saturday, 26 April. The symposium will also host the award ceremony for the 2014 Family Ties Promotional Awards*. Under the rubric "Reviews, Insights, and Prospects", the network is sending out this invitation to all those actively involved with sibling children and their families or who are interested in the issue of sibling children. If you have any suggestions or would like to register for the symposium, go to Rinne.Volker@Betreuungsnetz.org, Neuhaus.Ursula@Betreuungsnetz.org

** The next symposium organised by the FamilyTies Foundation will take place in Spring 2015.*



Participants at the Round Table organised by the Lebenshilfe Südschwarzwald discuss how to best identify and meet the needs and wishes of sibling children and their parents.

shop for the Siblings of Children with a Disability or Chronic Illness and the setting of three dates in support of siblings of disabled and chronically ill children. Boys and girls between the ages of 6 and 16 are being invited to take part in various activities that appeal to their creativity, such as writing and painting, role play, drama, and dance and movement, and to talk about good and hard times in the family, at school and with friends – and to have fun!

Klabautermann e.V. in Nuremberg: experienced partners meet for a round table discussion – for sibling children

The Klabautermann e.V. in Nuremberg and the Offene Behindertenarbeit der Lebenshilfe (Work and Support for the Disabled) have received donations for the development of a support network for sibling children with a focus on inclusion. The first round table held at the start of November demonstrated very clearly the breadth of options available and the willingness of all parties concerned to work together. Participating at the round table were: the C'nopfsche Paediatric Hospital, the Offene Behindertenarbeit der Lebenshilfe, the Active Citizens' Centre in Nuremberg and a psychologist already providing sibling children seminars.

The first exchange of experiences shall serve as a basis for the establishment of a more permanent collaboration to which each participant shall contribute their own knowledge and experience. It is the intention that a round table will be held once every three months. It is also planned to produce a flyer in 2014 detailing all the support for sibling children currently available in the

area and, for the very first time, to organise special days for sibling children.

Kerstin Heim in Marburg: achieving goals in collaboration with the city

The Kerstin Heim, a children's home for handicapped children and adolescents, has been working on a project in Marburg and has also established a Round Table for Sibling Children, which involves not only doctors, but also the Director of the City of Marburg Youth Welfare Office and an organisation that is currently engaged in the development of support for sibling children. The issue is now an established part of the city's Alliance for Families, which means that information for and invitations to parents and sibling children have been entered into a well-developed network.

Support for sibling children in the Southern Black Forest: establishing the needs of families will help to find collaborative partners in the area

The organisation Lebenshilfe Südschwarzwald has started the process of finding partners in the area who can contribute to the development of a support programme for sibling children. It is especially important in this area to identify the precise needs of parents and sibling children. A working group is currently putting together questionnaires for parents and sibling children, with the aim of distributing these in schools and in the organisations in the area that work with disabled or chronically ill children. The questionnaires are being based on a document drawn up by the Institute for Social Medicine in Paediatrics in Augsburg (ISPA) for the development of the Siblings' Club.

Action Day

A special day for special families

Over 250 families experienced Sibling Time at the Ravensburger Spieleland Theme Park

1,165 participants, over 250 families – the Sibling Time Action Day at the Ravensburger Spieleland Theme Park in Meckenbeuren was a very special day for very special families. On 6 October, the theme park opened its gates to sibling children, who are growing up with a disabled or chronically child in the family, and their families for a unique day of events.



Sibling Time ambassador, Peter Pux, gave a concert on the open-air stage.

The singer/songwriter from Ravensburg – himself a sibling child from a “special family” – introduced himself as an ambassador for the day and delighted families with his songs.

The Sibling Time action day depends on donations

The Sibling Time Day at the Ravensburg Theme Park was only made possible by the commitment of four organisations working together: the St. Gallus-Hilfe der Stiftung Liebenau (St. Gallus Liebenau Aid Foundation), the St. Jacobus Behindertenhilfe (St. Jacob Support for the Disabled), the Stiftung St. Franziskus Heiligenbronn (Heiligenbronn St. Francis Foundation), and the St. Elisabeth-Stiftung (St. Elisabeth Foundation). Christof Gräf made the point that such an event was only possible through donations, but also added that special families also deserved to have special days.

For further information:

Verena Rehm, tel: 07542 101402, verena.rehm@stiftung-liebenau.de, www.geschwisterzeit.de

“We are delighted to see so many people here today” were the welcoming words of Christoph Gräf, coordinator of the Liebenauer Netzwerks Familie (Liebenau Family Network), to the families, who all had one thing in common: a disabled or chronically ill child. On this day, however, the focus was on the children without disability or chronic illness, who usually have to take on responsibility at an early age and push their own needs in the background.

during the fire brigade game, which involved up to seven families competing against one another to put out a fire. What was so nice about the event was that it did not matter in the end how many points each family had won, as all the families received a certificate as a keepsake of the event at the prize-giving ceremony afterwards. The highlight of the day was the small concert given by Peter Pux on the open-air stage.

“Water, quick!” – the words frequently heard during the fire brigade game

To have fun and exchange experiences with other families – this was the common thread to all the family activities throughout this special day. It all began with each family being given a memory card when they first arrived at the theme park and being told to find its matching card and, in this way, to make contact with a partner family. “Water, quick!” – these were the words frequently heard



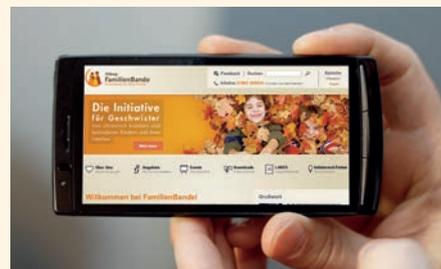
Over 250 families attended the Sibling Time action day at the Ravensburger Spieleland theme park.

Support FamilyTies with a charity text message

To help achieve the goal of every sibling child being able to access support in their area speedily and easily when needed, FamilyTies is supporting the development of regional support networks.

You can help support this goal by sending a charity text message to the number 81190. Text FAMILIENBANDE5 (for 5 EUR) or FAMILIENBANDE10 (for 10 EUR). 4.83 EUR and 9.83 EUR, respectively, will then go directly to the FamilyTies Foundation.

The cost of the text message (5 EUR or 10 EUR plus the standard text message charge for the mobile network provider) will appear in the following



month’s bill from your mobile network provider.* The FamilyTies charity text message is a simple way of supporting the work being done for sibling children and their families.

* Unfortunately, it is not possible to issue a donation receipt for text message charity funding.

Recommended books

by Marlies Winkelheide

“It is the others who are poor” von Pete Smith



A mentally ill mother abandons her children without warning, leaving behind four children from four separate marriages and a grandfather. All the children have their problems, but it is the eldest brother Sky, 17, who has to keep a watchful eye on his disabled ten-year-old brother and his attitude to life as well as on his grandfather, who is starting to suffer from dementia. The responsibility weighs heavily on him, but he does not want to call in the Youth Welfare Office, as he wants to avoid the family being split up. The setting for the story is convincingly portrayed and the relations between the siblings described frankly and ambivalently.

“Because I love Layken”

by Colleen Hoover



A very special sibling and love story about a schoolgirl and her teacher, about life and about the determination to carry on despite her mother's illness and her father's death. The protagonists, Will and Layken, share similar fates – they both have to cope with the loss of a parent and assume responsibility for their respective younger brothers in both families. This sensitive novel shows that openness and honesty are ultimately the best way to meet life's challenges.



Legal information

Content: FamilyTies Network
Editing and realisation: COMMPARTNERS,
info@commpartners.de, Holzkirchen
Publisher: Novartis FamilyTies Foundation
Öflinger Straße 44, D-79664 Wehr/Baden

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

Supported by



Prize-winner in the FamilyTies Promotional Awards 2013
in the category “Innovation/First Project”

SeeYou for Siblings – Until life is a success

Foundation for Family-oriented Aftercare, Hamburg SeeYou “CU”



Time for fun, games and chats as well as a place to share cares and anxieties – that is what sibling children and their families find at the Foundation for Family-oriented Aftercare SeeYou in Hamburg

The Foundation for Family-Oriented Aftercare, Hamburg SeeYou “CU” has set itself the target of improving the situation of chronically and severely ill children/adolescents and their families in the Hamburg area by providing preventative and rehabilitative support. The aim of the “Me too” project is to make parents aware of the particular situation of sibling children and to help them with professional advice. The Foundation also provides support from trained and qualified staff for a limited period. The staff visit the sibling children at home, discuss their wishes and anxieties and help them through play to better understand the situation of their disabled or chronically ill sibling. The support of the aftercare staff provides relief for parents and helps them to be more confident in coping with and looking after their disabled or chronically ill child. As a result, parents gain new strength and energy to devote to the needs of their healthy child as well.

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

The aim of the “Me too” project organised by The Foundation for Family-Oriented Aftercare, Hamburg SeeYou “CU” is to ensure that not only the disabled or chronically ill child, but also the sibling children receive care and attention. The support given to the families at home ensures that the individual and inno-

vative help provided caters to the specific needs of the sibling child by taking into account the particular family circumstances and relevant aspects of developmental psychology. This allows staff to provide needs-based support even to those families for whom the need for support is especially high. The multi-modal approach and the equal amount of time given to supporting both parents and sibling children have an impact on the entire family. All family members learn to cope better in their respective roles. Thanks to the work of the aftercare staff, a greater and long-term awareness of the unique needs of sibling children is maintained.



Sibling children not only attend joint events together with other sibling children, but also receive individual support at home from trained and qualified staff, thus providing relief for parents and putting the sibling children centre-stage.

Key information



Foundation for
Family-oriented Aftercare,
Hamburg SeeYou “CU”

Address: Liliencronstraße 130,
22149 Hamburg,
Germany

Internet: www.seeyou-hamburg.de
Email: n.jaehnic@seeyou-hamburg.de
Tel: 040 67377730 – Nicole Jähnic