FamilyTies LATEST – Issue 1 | 2014

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The new FamilyTies website is now online!

Working together for siblings – ONE platform for EVERYONE!

The new FamilyTies website provides support in equal measure for both the individuals concerned and organisations and institutions.



In designing the new FamilyTies website, our underlying concept was to make it easy for users to find support and information on what is on offer as well as making the search a fun and informative activity. The website is the outcome of experience gained through four years of collaboratiion with sibling support professionals and organisations.

The database, which now contains more than 200 possibilities of support and activities, is therefore the central feature of the new website. Organisations wishing to put the support they provide online can also upload photographs and easily update their entry at any time.

The extensive service section for the individuals concerned and interested parties contains a lot of helpful advice for siblings and their parents – e.g. dates, pointers to books and films – and an area with links to sibling children blogs, so that sibling children can exchange ideas, experiences and information directly with one another. For those professionals working for sibling children, there is an area with an interactive tool that allows them to enter the support they provide and any supporting documentation. The most important individual features of the website are described below.

Centre stage: the national support database

All organisations can use the website as a platform for presenting the support they provide.

At the heart of the website is the database with all the possibilities of support and activities provided for sibling children and their families. The

Editorial

Ladies and gentlemen, dear friends of FamilyTies,

Networking and the exchange of knowledge and experience are fundamental to the work of the Family-Ties Foundation. They have also been a guiding principle in the creation of our **new website** that went online in April. In this newsletter, we will be introducing you to our new website.

The deadline for entries to this year's Promotional Award has now passed and we have received 25 fantastic entries. The winners of the Promotional Awards 2014 will be announced at the Sibling Children Network Symposium in Wolfsburg on 26 April.

We would be delighted if you could check our website out at www.stiftung-familienbande.de and, as always, 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

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FORUM

FamilyTies Promotional Award 2014 at the Symposium of the Sibling Children Network Lower Saxony



The FamilyTies Promotional Award worth 5,000 EUR will be presented on 26 April 2014. Organisations and institutions offering sibling chil-

dren support for the very first time had until 17 March to submit their entry. This year, the award ceremony will be held at the Phaeno Science Centre in Wolfsburg in collaboration with the Sibling Children Network Lower Saxony at their 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". The symposium is aimed at all those actively involved in supporting the families concerned and their children or who are interested in the issue of sibling children. There will be talks from expects in the field, round table discussions and workshops. For further information and the programme of events, go to:

www.geschwisterkinder-netzwerk.de/ angebot/314.html



Workshops for sibling children start in Berlin

To put sibling children, their identity, experiences and needs centre stage, the Kindergesundheitshaus in Berlin held the first of three workshops for sibling children on 29 March 2014. Boys and girls between 6 and 16 years of age were invited to take part in creative activities and dance, drama, and exercise sessions. They were able to talk together with experienced professionals about wonderful and difficult situations that arise in the family, at school and with friends - but, above all, to also have fun. The project is one of a total of 4 pilot projects (Berlin, Nuremberg, Marburg, Southern Black Forest) that are establishing a new sibling children project on site in their cities/towns in collaboration with existing structures.

As with everything on the internet, our website is always subject to change. If you notice any errors, have any particular wishes or would like to make any suggestions, we would be delighted to hear from you at **info@stiftung-familienbande.de**



▶ navigation aid, search options and the display of the results simplify the search for appropriate support. If you wish to know more about the exact nature of the support being provided, this information is provided in images and explanatory texts. The map view shows you what support is available where.

2 Always up to speed

A quick look is enough to stay up to speed. The calendar of events displayed on the homepage allows the FamilyTies network to keep sibling support professionals, network partners and the families concerned abreast of current events. If you are a network partner, please make use of this option by simply sending us the dates of events via **info@stiftung-familienbande.de**. We will be only too happy to publish them on the website.

Area for sibling support professionals – exchange of knowledge and interactive input

Professionals involved in sibling support can register for the new closed area "Professionals Circle", in order to enter and make any changes to information about the support they provide. News and events from the network or information about new publications can also be found here. In addition, as a sibling support professional, you can use the area as a platform to present your methods and exchange ideas about them. Also to be found in this area is the standardised documentation format that has been used by the members of the FamilyTies quality circle for the past two years to document the support offered. Furthermore, the area provides a format for documenting individual modules of the support provided (for further details, see the following page).



The new area for families not only offers advice for siblings and their parents, but also recommends reading material specifically for young and adult siblings. In addition, FamilyTies is setting up an area for sibling children, parents and adult siblings to exchange their experiences in various blogs. From the middle of this year,



Working together for siblings

the network will have access to the Some members of the FamilyTies FamilyTies' very own blog to address quality circle the concerns of families and siblings. We will keep you up to date with developments in this area. New FamilyTies Blog Andreas Calas (left), Stiftung SeeYou Hamburg, and Ursula Neuhaus, Netzwerk für die Versorgung schwerkranker Kinder und **For families** From left to right: Corina Neidhardt, Sonnenstrahl e.V. Dresden; Sonja Richter, Bildungs- und Erholungsstätte Langau; Christa Engelhardt, Elternhilfe für krebskranke Kinder Sibling STORIES BLOGS for sibling children ing BOOKS mmended books for sibling children Leipzig e.V. You can get advice here You can get advice here The new area offers tips and help Eva Rauner (left), Klabautermann e.V. Nuremberg, and Tina Gerlach, VdK Sozialverband Bavaria. for the family

Documenting sibling support in a simple and straightforward manner

The documentation format helps improve quality

In collaboration with the quality circle, a set format for documenting sibling support has been developed, in order to ensure that the different and diverse sibling support provided is described in a uniform manner.

The aim is to collect and present the purpose, content, and methods of the respective support being provided using a common language and format. This provides the different sibling sup-

port organisations with a simple and useful tool to document their work. At the same time, it can serve the quality circle as a basis for the development of. for example, quality criteria and assessment tools. There is also a further bene-

fit; the common format makes it easier to compare the support provided, thereby encouraging and simplifying the exchange of ideas and information between the different organisations.

The documentation format has been de-

veloped as an online questionnaire and thoroughly tested. This questionnaire is included in the area for sibling support professionals on the FamilyTies Foundation website and therefore also

> provides organisations outside the quality circle with a tool to document the support they provide simply, quickly and efficiently using a common language and format. The description can then be printed out and filed. The area also enables

network partners to learn from one another. The plan is to present specific content and methods in sibling work using separate toolboxes, which will encourage organisations even more to exchange ideas and information and to learn from one another.

The quality circle

The FamilyTies Foundation established the quality circle almost three years ago.

The work of the quality circle is defined by the Institute for Social Medicine in Paediatrics Augsburg (ISPA). The purpose of the quality circle is to support the exchange of ideas and information between sibling support professionals, in order to improve the quality of the support provided. This involves documentation of the support, its evaluation and the consideration of quality standards and quality criteria.

The overall aim is to continually improve the quality of the support provided in all parts of the country.



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Recommended books

Mister Brendel – the story of my brother

By Gerd Brederlow and Heike Neumann



Bobby Brederlow, actor with Down's syndrome, has made films with some of the great of stars the silver screen, such as Senta Berger, Friedrich von Thun and Veronica Ferres. He has been awarded the Bambi and the

for his achievements. In his book, Bobby, Mr Bredi and Mister Brendel - the story of my brother -, Gerd Brederlow describes his life with his remarkable brother in a number of different settings - between filming, a workshop for the disabled and in an all-male household

The book is a portrait of a very unusual family and an impressive example of what can be achieved - even by those with Down's syndrome.



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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

Supported by



Golden Camera awards

Model agent Peyman Amin will be organising a fashion show for sibling children.

Down-Sportlerfestival WX

... on your marks, get set, run for joy at being alive!

Zest for life – that is what is awaiting the sportsmen and women taking part in the 12th German Down's Festival in Frankfurt-Kalbach, Germany on 17 May 2014. The festival is being held as part of the HEXAL initiative, "for a better future". Children and adolescents with Down's syndrome can compete against one another, revel in their success, and - even more importantly - have fun with their siblings and parents. The FamilyTies Foundation is also playing its part and inviting everyone to a Siblings Olympics. For the first time, there will be a drum workshop, Drums Alive, which siblings can attend together with their siblings with Down's syndrome. Participation in the festival is free. For news about the event, travel directions, accommodation and the impressions of participants in past years, go to www.down-sportlerfestival.de.

12th German Down's Sports Festival



The FamilyTies Foundation is running a programme of events of its own at the Sports Festival.

Super Summer Siblings Camp

Camp on the Chiemsee

The Sibling Association is holding the Super Summer Siblings Camp on the Chiemsee from 4 to 11 August 2014. The siblings of chronically ill children and children with cancer will have the opportunity to participate in various workshops and activities, such as canoeing, climbing and sailing. The event is open to siblings aged 7 to 12.







