FamilyTies LATEST – Issue 3 | 2014

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Successful networking

Comprehensive publication on Sibling Children

Working in cooperation with the Children's Network, the FamilyTies Foundation has produced a special publication focusing on "Sibling Children", which gives a voice both to affected individuals and experts.



unterstützt und entlastet werden +++ Pädiater sind häufig erste Anspredurch eine chronische Erkrankung oder Behinderung Probleme bei d dern auftauchen +++ Serviceteil zum Schwerpunktthema: Plakatv Familienbande, Fallbeispiele, Buch- und Linkempfehlungen

The collaboration between the Family-Ties Foundation and the Children's Network, the umbrella organisation for parent self-help groups, shows how successful networking can be. This has culminated in a special publication of Kinder Spezial on the topic of Sibling Children. "Kinder Spezial a magazine about children and adolescents with special needs" - is the members' magazine of the Children's Network.

This special 20-page issue gives a voice not only to experts in sibling support, but also to the siblings themselves. An overview of the wide range of services and activities available to siblings shows how families can be supported and their lives made easier. The description of a standardised documentation shows how it is possible to assure the quality of the wide-ranging services that are available. In addition, the paediatrician Dr Stephan Nolte focuses on the overall family situation. At the end of this special themed issue is an information section with tips for further reading and a list of contacts/ links

> The publication is suitable for anyone who works with sibling child-

ren on a daily basis. It can be ordered via info@stiftung-familienbande.de

This magazine can also be downloaded as a PDF from www.stiftungfamilienbande.de. Further information on the Children's Network and Kinder Spezial can be found at www.kindernetzwerk.de and www.kindernetzwerk.de/zeitschrift-kinder-spezialdes-kindernetzwerks/

Editorial

Dear friends of FamilyTies,

"Together for Siblings" is our motto - and we feel that this is very nicely reflected in our special themed publication on Sibling Children, produced in cooperation with the Children's Network e.V. (see standfirst). Why not see for yourself?

This special edition of FamilyTies NEWSLETTER includes no fewer than three items that address the topic, inclusion: the interview at the independent ,Freie Bühne' Theatre in Munich(FBM)andthetworeportsonthe winners of the FamilyTies Promo--tional Award 2014, which focus specifically on how nature can help to promote inclusion and self-determination

We would also like to take this opportunity to once again make a special mention of the Breisgau Parachuting Association (BVF) in Freiburg, which staged a fabulous fundraising event in aid of sibling children. When asked why, BVF president Helmut Lang-Dahlke said: "Affected siblings often get a raw deal. Parachutists are familiar with this scenario - we too are always being overshadowed by the light aircraft lobby."

Wishing you happy reading, as ever. Together for Siblings!



Mark Never. Chairman of the Novartis FamilyTies Foundation Board



Irene von Drigalski CEO, Novartis FamilyTies Foundation

Working together for siblings

FORUM



Film tip: "Simple Simon" (Sweden, 2010)

18-year old Simon has Asperger's syndrome. He likes space, circles and - most of all - his brother Sam, who looks after him lovingly. When Sam moves in with his girlfriend, he takes his brother with him. But Simon's behaviour, and his compulsion to control, place such a strain on the relationship between Sam and his girlfriend that she ultimately leaves him, whereupon the two brothers' otherwise very ordered world is plunged into chaos. To make everything "normal" again, Simon goes on a mission to find Sam a new girlfriend. Unfortunately, Simon knows nothing about love and doesn't understand emotions - but he does have a scientifically foolproof plan.

A film full of hilarious moments, which portrays the relationship between the two brothers in a highly imaginative and moving way.



Pinky takes to the air in support of sibling children – and FamilyTies says thank you for the fundraising event that took place from 5 to 7 September!

Winners of the 2014 Promotional Award

Learning from one another in nature

The aim of the "Garden Children" group is for children with and without disabilities to learn from and with one another – and that they should do so surrounded by nature. This shows sibling children that support can also come from outside the family.



The team from Mittendrin Hannover in front of their drop-in centre

"Learning from one another in natural surroundings, simply being a child, having fun outdoors": These are the aims of the "Garden Children" group. This pilot project is intended to bring children aged 6 to 12 years into closer contact with nature. Whether they are carving, model-making, building, planting or just racing around the summer house – the important thing is that sibling children should be given the attention they deserve.

"Here they can set aside the responsibility that they feel for a disabled brother or sister and allow themselves to receive the attention they deserve", says Birgit Rauschke from Mittendrin Hannover, an organisation that endeavours to integrate people in Hannover with disabilities into all areas of education and life.

Inclusion and siblinghood belong together

With its new group activity programme for sibling children, which is due to start in February 2015, the organisation has created a new arena for children from inclusive primary schools. "Children living in central Hannover have little opportunity to find out what it is like to live in natural surroundings. By participating in shared recreational, gardening and land-art activities, they can first of all bond into a group and then later begin



The aim is for children to learn from and with one another in natural surroundings

to discuss such topics as their feelings and experiences of being different and of belonging from their different perspectives", explains Birgit Rauschke. "And as inclusion and siblinghood belong together here, the participating siblings find that in an inclusive group they are regarded in exactly the same way as their brother or sister and that social resources can also come from outside the family."

The organisation has received the FamilyTies Promotional Award 2014 for pioneering this concept. The jury regarded the approach of applying the concept of inclusion to siblings as a particularly outstanding contribution. It also commended the fact that the activity programme on offer has been drawn up as a potential pilot project, which can be adopted by other primary schools.

Key information

Established: 2007 Target group: Private individuals, institutions and other organisations Age: no age restrictions Anschrift: Mittendrin Hannover e.V. Kontakt-und Beratungsstelle Burgstraße 7 30159 Hannover Tel.: +49 (0)511 / 4500644 e-mail: beratung@mittendrin-hannover.de

Working together for siblings

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"Learn about life!"

The ,,Learn-About-Life Survival Hike in the Wilderness" for siblings is designed to enhance their everyday lives and self-determination, earning this programme the FamilyTies Promotional Award.



With cups they have made themselves out of coconuts and a nomad tent in their backpacks, the children set off on their adventure, navigating their route with map and compass. As there is neither hot and cold running water nor electricity, every evening is spent cooking over an open fire and philosophising about their experiences that day.

Under the motto "Learn about life!", Wupperlebnis e.V. offers sibling children aged 12 to 18 an eight-day wilderness hike across the Eifel volcanic region. "This wilderness survival experience is designed to give the participants a special opportunity to learn valuable life lessons as well as the chance to put these intensive experiences into practice in their everyday lives", says Manuel Spors of Wupperlebnis e.V.

In no way is this a question of enduring excruciating, life-threatening situations. Instead it is all about independently overcoming extraordinary, but fascinating challenges and – based on (re-)discovered needs – collectively devising appropriate strategies for dealing with everyday demands and challenges through resource- and solution-oriented initiatives.

First sibling-related programme from Wupperlebnis e.V.

The "survival hike" concept was devised as a intensive preventive educational tool. The primary aims are to strengthen life skills and thereby maintain the health of affected siblings. The wilderness hike is the first independent project from Wupperlebnis e.V. that is specifically geared towards siblings who are growing up - or have grown up – with someone who is disabled or chronically ill. "Our aim with this pilot project is to expand the exceedingly limited range of activities currently available in the densely populated Wuppertal area", says Manuel Spors. In addition, Wupperlebnis e.V. is currently engaged in developing and implementing a wide range of other activities for sibling children throughout Germany.

This programme won Wupperlebnis the FamilyTies Promotional Award 2014.

Key information

Established: November 2013 Target group: siblings aged 12-18 years Address: Rutenbecker Weg 159, 42329 Wuppertal Tel: +49 (0)163 76 96 75 9 (Manuel Spors) e-mail: info@wupperlebnis.de www.wupperlebnis.de

The jury particularly welcomed the fact that the initiative is also aimed at adolescents from difficult family backgrounds. Furthermore, it commended the proposed use of the LARES early detection tool and the fact that one team member is to be trained as a "specialist in sibling children".



At the 1st International Congress of General Practitioners in Bonn: Irene von Drigalski and Prof. Klaus-Dieter Kossow, FamilyTies Foundation board member

Working together for siblings

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,Freie Bühne' Independent Theatre, Munich

The theatre with a difference

Inclusion is a topic that evokes contradictory reactions. For siblings more than anyone, inclusion - especially in school - is a delicate matter. Who comes to the fore, and how? This is why FamilyTies wishes to showcase the independent ,Freie Bühne' Theatre in Munich (FBM) - a particularly successful example of inclusion, whereby people with and without disabilities contribute their talents and ultimately everybody benefits from it. Below is an interview with the journalist Angelica Fell, lead chairperson of the FBM board and mother of three children, of whom the youngest son has Down's syndrome.

"What fascinates me most about the ,Freie Bühne' Theatre in Munich is the fact that it will enable people with and without handicaps to perform together. After all, the truly marvellous thing is surely that every member of the community is able to develop his or her talents and receives recognition for doing so. And it shows how colourful and joyous inclusion can be. This sort of positive interaction is often not so easy in everyday life – we know that from our work at the FamilyTies Foundation."

Mark Never, Chairman of the Novartis FamilyTies Foundation Board



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We value your opinion:

Please let us know what aspects of FamilyTies NEWSLETTER you have enjoyed or what could have been done better. If you would prefer not to receive the newsletter, please send a brief e-mail to: info@stiftung-familienbande.de

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Question: What is so special about the ,Freie Bühne' Theatre in Munich? **Fell:** We are the first theatre in Bavaria where people with and without disabilities will be performing professionally on an equal footing.

Question: What exactly does that mean? **Fell:** Half of the ensemble on stage have a disability and half do not. This also applies to technical roles such as photography and editing. And incidentally, half of our management board are siblings too.

Question: In reports on efforts to promote inclusion in schools, we often hear of affected siblings being called upon as experts, so they find themselves cast in a supporting role and are consequently, as it were, ,sidelined'. What is the situation at the FBM?

Fell: In our theatre, people with a disability can finally bring their theatrical talents onto the stage, which creates an ensemble that lives on the strengths of all, rather than just relying on certain individuals. Did you know that there are no drama schools that accept people with an impairment? This means that everybody – companies and audiences alike – misses out on so much.

Question: How can the actors with an impairment match the professionalism of the other half of the company without having had the same training?

Fell: We have special coaching sessions, which provide the necessary knowledge and stagecraft that others learn at drama school. But the outcome of this process is not the same as with those members of the team who don't have a disability. Without wishing to overgeneralise, it is true to say that those members of the company with a disability bring onto the stage a very particular type of emotionality that I have yet to see in any other actor.

Question: How is the project being financed?

Fell: Firstly there is a great deal of voluntary involvement. In addition, we have set up a funding body, which enables people to support our work by making an annual



donation of 50 EUR or more. So far we have around 30 members and many prominent sponsors, such as Veronica Ferres, Michaela May, the President of the Federal Association for People with a Mental Disability, Ulla Schmidt, and our Patron, Bavaria's Minister of Social Affairs, Emilia Müller. In addition, there are donations (e.g. the very generous donation of 20,000 EUR from the Sparda Bank), grants from the Department of Culture in Munich and funding from various foundations.

Question: What were the most striking lessons that you learned while setting up the FBM?

Fell: German charity law is a real challenge. We are recognised as a non-profit association that promotes art and culture, but the Munich Tax Office has difficulties recognising our ,charitable' purpose - a rather unfortunate term. This is apparently because actors without a disability will also be involved. But this is actually our aim - inclusion, - that everybody should work together, rather than working, as it were, on different planets. In real terms, this means that we miss out on a lot of potential funding opportunities, since many companies, foundations and organisations will promote charitable purposes, but not cultural ones.

Question: What was one of the most memorable experiences when you were setting up your theatre company?

Fell: It came after the first coaching session, when Bobby Brederlow happily and loudly proclaimed to the entire company: "I want to stay here!"

Question: When is the first performance? Where can one buy tickets and find out more?

Fell: Information can be found on our website at www.freiebuehnemuenchen. de. On 17 November, there will be a charity performance in the Munich Indoor Riding Arena (Reithalle). And we are planning to stage our first evening performance in early 2015.





