FamilyTies LATEST – **Issue 2** | 2013

Infoline FamilyTies: Tel. 01805 322633
German landline €0.14 min. – Mobile: €0.42 min.

Working together for siblings

Editorial

**Ladies and Gentlemen,
Friends of FamilyTies,**

"...to get them out of the shadows and into the sunlight, see them blossom and develop, hear them laugh." That's what Dr. Assia Kemih, a specialist in general medicine, wishes for these special "Geschwisterkinder" (siblings, here specifically: mixed healthy and handicapped siblings). Dr. Kemih is a single mother raising a severely handicapped son and an older daughter. She reveals in an interview how the family masters the challenges of daily life and how important supporting siblings is.

The work of the Bundesverband Herzkranke Kinder e.V. (BVHK Federal Association for Paediatric Cardiac Patients) makes it clear how important it is for the parents of these special siblings to be aware of and accept their own wishes and needs. As the winner of the FamilyTies Advancement Award 2013 in the category "Work with Parents", the BVHK is featured in this issue.

The Marlies Winkelheide specialist conference at the end of April 2013 in Bremen (www.geschwisterkinder.de) reflected the spirit of Janusz Korczak, a Polish physician, author of children's books and educator. An extract from the welcoming speech by Herlinde Schneider from the Executive Board of FamilyTies provides an overview of developments over 30 years of helping special siblings.

Have fun reading! Supporting Siblings!

Mark Never,
Chairman, Executive Board of the Novartis foundation FamilyTies

Irene von Drigalski,
Executive Manager of the Novartis foundation FamilyTies

Foto: Fotolia/Sonya Etchison

Prizewinners in practice

Families with a Big Heart Need Strength – that's the motto for the everyday work of the Bundesverband Herzkranke Kinder e.V.

Families with a Big Heart Need Strength

Bundesverband Herzkranke Kinder e.V., winner of the FamilyTies Advancement Award 2013 in the category "Work with Parents"

The Bundesverband Herzkranke Kinder e.V. comprises mostly parents of young cardiac patients working on a voluntary basis. It is THE self-help coordination hub in Germany for paediatric cardiac patients and their families.
To reach the young cardiac patients, their parents and their siblings, informative and recreational weekend events full of variety are on offer, providing activities for all family members. Parents can participate in a wide variety of seminars while the kids are taken care of in accordance with their individual needs.
The main aim of the workshops and lectures is to show parents how important it is for them to be aware of and accept their own wishes and needs: Only parents with lots of pep and self-confidence are up to the task of preparing both young cardiac patients and their siblings for independence in later life.

Praise by the Jury of the FamilyTies Advancement Award:
"Using a very well-founded and innovative approach, the Bundesverband Herzkranke Kinder e.V. is continually ex- ➔

Basic information

Bundesverband Herzkranke Kinder e. V. (BVHK)

(BVHK - Federal Association for Paediatric Cardiac Patients)

Founded: 1993
Address: Kasinostraße 66,
52066 Aachen
Internet: www.herzklick.de
Email: hermine.nock@bvhk.de
Tel.: 0241 912332 – Hermine Nock

Forum

Tip: KinderKlinikKarten Memory Game

Repeated visits to the hospital in cases of severe chronic or life-threatening illness are debilitating, both for the sick child and the healthy siblings. The KinderKlinikKarten Memory Game was developed by Leipzig psychologist Florian Schepper together with colleagues. It provides an excellent way for children to prepare for, and then post-process, medical examinations. Children can sort the 52 picture pairs of the card game in the order of easiness or difficulty and collect the situations they have already been through as "trophies". This enables the physician, psychologist or other caregiver to see which examinations the child is afraid of. The game is also suitable for helping healthy siblings to process experiences of daily life in a playful manner.

Order at: www.mvsv.de

Foto: Yvonne Tänzer

Christoph Gräf, Liebenau Foundation (left) and Irene von Drigalski, Executive Manager of the Novartis foundation FamilyTies (right), present the FamilyTies Advancement Award 2013 to Anett Pöpplein, Bundesverband Herzkranke Kinder e.V.

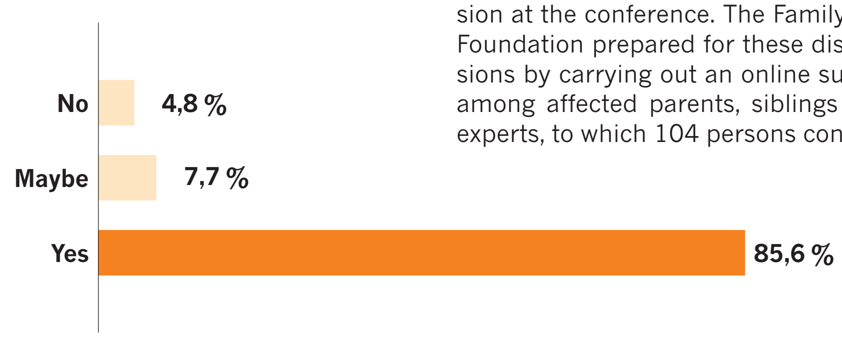
panding the existing offer of family services with well thought-out modules for siblings. These include programmes for imparting knowledge about the diseases involved, relaxing activities, experience exchange, individual conversational sessions, seminars and support for founding self-help groups. The free-time activities involve the entire family, including parent coaching to enhance families' psychosocial resources. There are plenty of fun activities for the children as well. In this way, the BVHK does justice to the complex familial interactions between parents, paediatric cardiac patients and their siblings. The intention of the prize is to honour the work of the BVHK and to ensure that the siblings of young cardiac patients will continue to benefit from such specific offers to further their development in the future."

Online survey

Focus on "Inclusion"

What does the term inclusion mean for patient siblings? Are we prepared for this question? Above all, will we have the right answers to implement the stipulations of the Disability Law Convention, i.e. complete introduction of the principle of inclusion in all German schools in 2013? These questions were the subject of lively discussion at the conference. The FamilyTies Foundation prepared for these discussions by carrying out an online survey among affected parents, siblings and experts, to which 104 persons contributed. 85.6% of those surveyed stated that the principle of inclusion should take the special situation of the siblings of patient children into consideration. On the other hand, nearly 80% expressed the opinion that schools / teachers are not prepared for the specific situation of these special siblings. At any rate, nearly 38% of those surveyed were of the opinion that children would experience a positive change once they attended the same schools as their sick or disabled siblings, but only on condition that the schools established the necessary programmes – for teachers, pupils, parents of patients and, of course, the parents of the other pupils.

"Do you think the principle of inclusion should take the special situation of the siblings of patient children into consideration?"



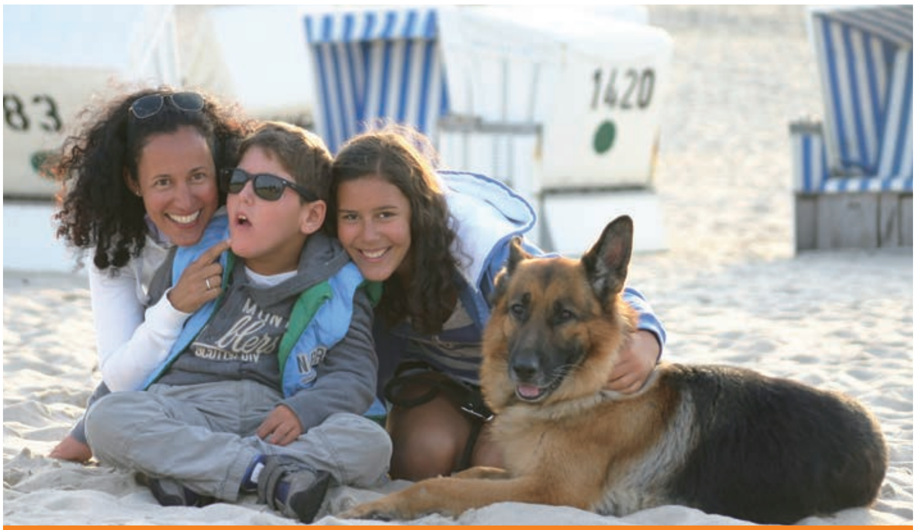
Source: Online survey, February 2013, FamilyTies Foundation **(n=104)**

Go to www.stiftung-familienBande.de for more survey result.

Interview

"I want to hear them laugh."

Dr. Assia Kemih, a specialist in general medicine and psychotherapist, on the value of the work of FamilyTies for special siblings and her own life experience as a single mother of two children.



Happy family – Dr. Assia Kemih, son Alvin (11), daughter Alisha (13) and last but not least "therapy dog" Willy enjoy a day at the beach.

Irene von Drigalski (FamilienBande): How did you find out about FamilyTies?
Dr. Assia Kemih: There was a report on FamilyTies during a CME (continuous medical education) session. At first I thought "What's the point in that" – but when I got the message it was "Wow, great!" It's good that there are organisations like that because as many people as possible should be aware of the situation. It's too much to manage on one's own.

Irene von Drigalski: Tell us more about that "Wow!" effect.
Dr. Assia Kemih: My son Alvin (11) has been severely handicapped since birth. He has a severe cardiac defect (HRHS - hypoplastic right heart syndrome) with a brain haemorrhage. He needs continuous care. I get up two or three times a night to turn him over – he can't do it alone. His older sister Alisha (13) is therefore one of these special siblings. It wasn't until FamilyTies came along that I really became aware of this special situation. I am aware of the problems as a physician and can now see things more clearly, above all that you can get help!
Irene von Drigalski: How do you handle the special sibling situation in your family?
Dr. Assia Kemih: We really talk about it a lot. My daughter is very well informed about her brother's illness. We are a physician's family and we talk openly about everything at the dinner table. I work part-time to have enough time for both children. I'm thankful that this is possible since I work in a practice together with my mother and brother. My family also provide a tremendous amount of support and the two kids get lots of attention from them. Of course we also have Willy, our "therapy dog". Willy has a wonderfully calming effect on us all.

> "When both of you fall down, you're the first to get up again."
>
> Dr. Assia Kemih

Irene von Drigalski: Does your daughter have questions about her personal situation?
Dr. Assia Kemih: She once asked me at bedtime, "Why is my life so hard?", by which she meant both my separation from my husband and her handicapped brother. I told her she has a great advantage over her girlfriend at school whose life isn't really hard at all – because she's learning to handle difficult situations. When I said, "When both of you fall down, you're the first to get up again", it convinced her.

Irene von Drigalski: You initiated two donations to the FamilyTies Foundation. Why was that?
Dr. Assia Kemih: Some patients asked me about it. They had put on a street party and were looking for an organisation to which they could donate the 500 Euros they had collected. They immediately became enthusiastic about the FamilyTies Foundation when I recommended it to them. In 2012 I helped found the Lions Club Dreisamtal. I proposed there that we should donate 500 Euros to the FamilyTies Foundation – and once again everybody agreed to it.

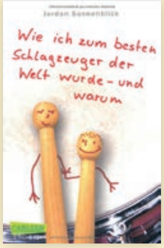
Irene von Drigalski: What would you recommend to others who want to do something for these special siblings?
Dr. Assia Kemih: Talk about it. Make sure the subject is not taboo, that you don't have to hide, that it's important to donate what you can so a solid network can be established!

Irene von Drigalski: Dr. Kemih, if you had three wishes, what would you wish for special siblings?
Dr. Assia Kemih: ... to get them out of the shadows and into the sunlight, see them blossom and develop, hear them laugh.

Literature tips

How – and why – I became the world's best drummer

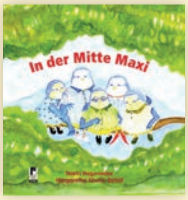
by Jordan Sonnenblick



"I always thought having a brother was the worst thing in the world. But now I know not having one would be much worse." (p. 204)
The book, written from the point of view of the older brother of a boy with cancer, describes the illness and all the challenges it entails for family life. The feelings of the sibling, the compassion, the cloak of silence over the family, not being understood at school and the extra attention and consideration demanded repeatedly as a matter of course are described within the framework of an interesting plot.
(Review by Marlies Winkelheide)

Maxi in the Middle

by Maria Hageneder



Mimi, a blue tit girl, tells the story of her family, which is characterised by the special challenges presented by her brother Maxi's disability. Maxi is different. Though old enough to fly, he can't. He is often very slow. The parents have their hands full with Maxi, which often makes life difficult for Mimi and her sister Lilli. The book shows what they experience as the siblings of a handicapped child, how they react to their unusual situation – and what they learn for life.

Stiftung
FamilienBande
Gemeinsam für Geschwister

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
NOVARTIS SANDOZ HEXAL Alcon

Specialist Conference

Special Siblings – A Lifelong Issue

Experts in their own right – Special siblings of all ages had some very personal things to say at Marlies Winkelheide's specialist conference in Bremen.

What moves siblings was revealed in impressive fashion at the specialist conference "Janusz Korczak – Challenges In Supporting Siblings. Learning With and From Siblings – 30 Years of Development in Sibling Seminars", which took place on 19–20 April 2013 in Bremen.
Marlies Winkelheide (www.geschwisterkinder.de) was the first to focus her work on the needs of special siblings. She recognised that special siblings need to be taken seriously when it comes to their life situations. They are experts in their own right, and that was how they presented themselves at the conference – reading their own texts, discussing and sharing their stories. There were about 150 participants, who profited from just listening to these children or by actively participating. It was all about listening, watching and learning that the questions are often more important than the answers. That is exactly what Marlies Winkelheide has been doing for over 30 years. The welcoming speech by Herlinde Schneider from the Executive Board of FamilyTies provides a review of these 30 years:

Extract from the welcoming speech by Herlinde Schneider

"How much courage does it take to devote one's life and work to a central issue that others don't even see? That is what I ask myself when I consider your life, dear Mrs. Winkelheide. And what is necessary besides courage? Over 30 years ago you began holding special sibling seminars. You were THE pioneer and set us a shining example from the very beginning. Over the years you have developed a way of seeing people and situations that is certainly unique. We haven't met as often as I would have liked, but when we have met I always felt I was being perceived as the person I was. How many life situations have you supported? Hundreds, even thousands? In my view it takes courage to look, to see and to say what you see. I would like to thank you for this with all my heart. Only a person with a big heart can reach the hearts of others. You reached mine when it came to Novartis getting involved in the special siblings issue. At the end of 2009 Novartis finally held the first FamilyTies conference. We wanted to discuss with experts – in particular with you – whether a national initiative for special siblings would make sense. This initiative has now turned into a foundation. We are proud of this. I am proud that you, dear Mrs. Winkelheide, had the courage to open your heart to FamilyTies. Thank you – Supporting Siblings!"

For over 30 years, Marlies Winkelheide has been pursuing the question of what is important to special siblings and what affects them, in keeping with the motto "Learning with and from siblings".

Preview

SuSi has its scientific debut

Read more about the prevention programme "Supporting Siblings (SuSi)" in the 03/2013 issue!