

Working together for siblings



Poster competition

More than a thousand words can say

Young artists powerfully put sibling children centre-stage.



“Mum has to look after Lena”
1st prize: Julia Pol (aged 23)

“With my poster, I wanted to show that sibling children often have to be more independent and perhaps even more grown-up, as their parents have less time and energy for them, because they have to look after a sick or disabled brother or sister. But every child still needs the opportunity to experience what it is like to just be a child – that’s why I think of healthy siblings as little heroes.”

These are the words of Julia Pol (aged 23) explaining her work “Mum has to look after Lena”, which shows a fiercely determined boy with a saucepan stuffed on his head and holding a cardboard sword. He has to fight for his place in life, while at

the same time taking on far more responsibility than other children of his age.

The poster by Julia Pol was one of the entries to the competition organised by FamilyTies for design students at the Offenbach School of Design on the subject of sibling children and was awarded first prize. Of the 34 entries, three other entries were also awarded prizes by the jury composed of communication specialists of the competition organisers.

Isabel Blumenthal (aged 25, 2nd prize) tried to portray the feelings of the healthy child. She explains that her →

Editorial

Ladies and gentlemen, dear friends of FamilyTies,

Just how impressively ambivalent feelings such as loneliness, sadness or even anger can be portrayed in art is demonstrated by the entries for the poster competition for design students under the heading, “Don’t I count too? The siblings of chronically ill or disabled children need more attention”. The four prize-winning posters have already been displayed at several events and conferences to much acclaim.

Bolstering feelings of self-worth through positive experiences is the primary goal of the Sibling Weeks that are organised annually for sibling children by the Society for Mucopolysaccharidoses (MPS) e.V. As the prize winner in the Family Ties Promotional Awards 2013 in the category “Innovation/First project”, the work of the Society for MPS will be described in greater detail in this issue.

Making sibling children strong – this was the aim of the prevention training “Supporting Siblings” (SuSi), which was developed for social institutions and presented at the 8th Workshop Congress of the German Society of Psychology in Trier. The response to the talk shows that this project addresses an important issue.

We hope you will enjoy reading this issue. Working together for siblings!



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



Irene von Drigalski,
Executive Manager of the Novartis foundation FamilyTies

In the media



Spiegel online

*Siblings of sick children:
Support for the emotional turmoil*
Wednesday, 21.08.2013

Love, jealousy, sadness, anger – many siblings have to confront these ambivalent emotions. But only very little of what is going on inside siblings is expressed on the outside. And even if it was, parents would often be unable to react, because they are so emotionally caught up in their own cares and anxieties. This is the assessment of a team of scientists working with the psychologist, Florian Juen from the University of Innsbruck. This is why, in their opinion, it is important to provide support for siblings to enable them to learn how to cope with the emotional turmoil inside them. This is also confirmed by Irene von Drigalski, Managing Director of the FamilyTies Foundation. **Full article at www.spiegel.de/gesundheit**

ZDF – Mona Lisa

Being strong for her brother
Saturday, 29.06.2013

Paulina's (aged 12) brother Tristan has a rare brain disorder. Tristan is 9, but has the mental age of a 3-year-old. He needs his mother and sister's full attention. The mother can't help but feel that Paulina has once again had far too little attention. There are times when, even for a strong girl like Paulina, it gets too much that the focus is always on her brother. Siblings can build up emotional stamina and their self-confidence in seminars organised by the Lebenshilfe Bremen. Siblings like Paulina have to grow up very quickly. However, regardless of the difficulties that the responsibility may bring, she wouldn't want to change her brother. **Full programme at www.zdf.de/ZDFmediathek**



poster is an attempt to convey the idea that the neglected child not only feels like an outsider, but also genuinely has the feeling that the rest of the family has turned into some large and insuperable monster.

Tatjana Prenzel's (aged 21, 3rd prize) approach was different. She wanted to convey loneliness and exclusion. She explains that her poster focuses solely on the sibling child, who is left to his or her own devices. From this perspective, it is clear that the only thing that counts for the sibling child is the moment when his/her sister or brother gets more attention than he or she does.

The title of the poster by Martin Dörr (aged 22, 3rd prize) is "Where is Tim?" It shows a fictitious to-do list for a mother with two children, one of whom is disabled and the other, the healthy Tim. Most of the items on the list revolve around caring for Max and as Martin Dörr explains, these take up so much of the parents' time that they forget about picking Tim up from school. The healthy sibling is easily overlooked in the daily routine. It is only at 11 at night that the panic-stricken parents suddenly ask: "Where is Tim?"

At events and conferences, the posters have proved time and again to be invaluable in stimulating highly personal discussion. It doesn't matter if the viewers are paediatricians, parents, sibling children or professionals – nobody who intensively reflects upon the pictures can fail to be touched by what they see. And, in terms of numbers, there is no one overall winner, as each work

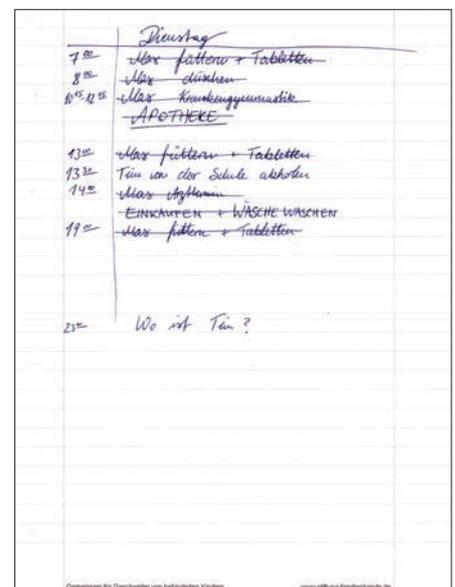


"Don't I count too?"
3rd prize: Tatjana Prenzel (aged 21)



"3-headed sea monster"
2nd prize: Isabel Blumenthal (aged 25)

arouses different feelings in the viewer. Whereas the defiant and angry expression on the face of the boy in "Mum has to look after Lena" has an almost magnetic attraction for some ("That's exactly how I felt, only I wouldn't have been able to find the right words"), others were equally strongly repelled by it. They recognise sibling children more in the picture of the girl sitting with her teddy by Tatjana Prenzel: "Some siblings turn away and think that only Teddy is there for them" was the comment of one deeply touched grandmother. "That's exactly what it's like" was a frequent comment from parents who couldn't stop looking at "Where is Tim?" That a bit of humour is also not amiss in addressing the issue is demonstrated by the "Three-headed sea-monster", which is appreciated by many for whom the other pictures are too serious. As a paediatrician from Hannover put it, no one poster is better than the others, as each highlights a different aspect of this multi-layered issue.



"Where is Tim?"
3rd prize: Martin Dörr (aged 22)

Prize winner in the FamilyTies Promotional Awards 2013 in the category "Innovation/First Project"

In search of oneself

Society for Mucopolysaccharidoses (MPS) e. V



Discovering your strengths, expressing your needs or simply being able to let yourself go - this and much more is provided by the Sibling Weeks organised by the Society for Mucopolysaccharidoses (MPS) e.V.

The Society for MPS e.V. works nationally to try and ensure that children with the incurable disease mucopolysaccharidosis can lead the lives they choose, i.e. can determine their lives themselves. The annual Sibling Weeks also provide an opportunity for affected sibling children to exchange experiences and allows them to discuss the issues that affect them in a safe environment. The subject of the 2013 event - ME -

focused on helping sibling children to find their own identities within the conflicting demands of normal everyday life and extraordinary family circumstances. This allowed sibling children to address their own needs and expectations and bolster their feelings of self-worth through positive experiences.

The primary aim of the Sibling Weeks was to enable sibling children to discover and develop their personal strengths through their creative involvement in the development and completion of a film project on the subject ME.

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

With its video action week on the subject ME, the MPS e.V. has developed an innovative and very effective model. Film as a modern medium with a special appeal for teenagers has an important role to play both in the work with sibling children at a low threshold level (leisure activities up to and including self-reflection) and at the intensive (treatment)

care level. Thus, during the planning stage of the film, the whole concept of ME is developed as a first step. This is then actively and creatively interpreted during the filming. In the process of editing the filmed material and when viewing the completed film, each of the sibling children have the opportunity to reflect and work on the development of his or her own self, as an individual. The medium of film is therefore an extraordinary opportunity for them to articulate their feelings in a creative manner and through play.

Key information

Society for Mucopolysaccharidoses (MPS) e.V.

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Now it's My Turn!

The Network for Siblings organised the largest summer camp for sibling children in Germany

"I go on the SuperSummer Camp, because I really enjoy getting to know many other children, who either have been through the same as me or are in the same situation as me. We simply understand one another."

These are the words of 12-year-old Miriam, who has a brother with cancer. Miriam was one of 60 children and teenagers at the sibling camp "Now it's My turn!", which was held at the Irmen-gardhof of the Björn Schulz Foundation at Chiemsee from 15 to 24 July.

The SuperSummer Camp was organised by the Network for Siblings. This Network is made up of eight separate organisations in the new Federal German states that have got together and formed a network with the aim of providing high quality support for sibling children. In recognition of this form of networking, the Network received the

FamilyTies promotional award for special services to working with siblings in Nuremberg on 15 March 2013.

The children were given loving and individual support over a period of ten days by a total of 20 carers. In the mornings, they learnt in a playful and child-friendly way about the diseases affecting their siblings or were given help in developing specific life or problem-solving skills. In the afternoons, they had the opportunity to get to know one another better through a variety of leisure activities such as building models, rafting or climbing.

And no sibling child missed out. As Florian Schepper, psychologist with Parental Support for Children with Cancer, points out, the high care ratio of three to four children per carer truly lived up to the slogan for the camp, "Now it's My Turn!" They didn't just

want to have a good time with the children, but they also wanted to be there for them individually as someone they could turn to if they wanted to discuss their problems.

And what did Miriam like best about the SuperSummer Camp? "I really enjoyed the trips. The rafting was great. And you quickly make friends here."



Together at the Summit: On a long hike, the siblings were able to enjoy nature and the countryside, let off steam and simply have fun

Recommended books

“... and Nobody Cares About Me!”

by Ilse Achilles



In the 5th updated new edition, the author describes how siblings of disabled and chronically ill children develop and what opportunities and risks are associated with these particular family constellations. She shows through many examples how parents and the social environment can support siblings and avoid or minimise dangers. Included in the 5th edition for the first time is, amongst other things, an article about the FamilyTies Foundation. The book successfully combines reports by affected children and adults of their experiences, research reports, and practical help and advice.

“Janusz Korczak - Challenges in Supporting Siblings”

Learning with and from siblings



Siblings from all age groups as well as staff and speakers presented quite personal papers at the Janusz Korczak Symposium held in Bremen on 19/20 April 2013. These papers and the experiences of 30 years of sibling support by Marlies Winkelheide can be found in the documents from the symposium.

The volume can be ordered for 20 euros with free delivery via the Janusz Korczak Sibling Library (www.geschwisterbuecherei.de, geschwisterbuecherei@t-online.de).



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Latest

SuSi and the scientific community

“My child is more self-assured and has more confidence since SuSi” or, “My child is able to express his needs more clearly, is more aware of his feelings and can communicate them better.” This is what parents say about their children after they have taken part in the SuSi Prevention Programme. SuSi was developed by the Institute of Social medicine in Paediatrics in Augsburg (ISPA) in collaboration with the FamilyTies Foundation and the University of Flensburg with the aim of enabling sibling children to further develop, through play, life skills such as dealing with conflict and feelings of self-worth. At the same time, sibling children learn, among other things,

how to bring up issues themselves, discuss them with their parents and then resolve them together.

On 9 May 2013, SuSi was presented at the 8th Workshop of the German Society of Psychology (DGP) in Trier. As Kerstin Kowalewski, ISPA, points out, the fact that a talk on the subject of sibling children was accepted for the symposium of the congress demonstrates that they have adopted a sound and scientifically accepted approach with their training. They will further develop and validate SuSi. To this end, they are collaborating with other organisations and passing the training on to them at their premises.

In addition to the talk on SuSi, the ISPA SiblingsCLUB, also supported by FamilyTies and providing five group and individual events, was presented in a 90-minute poster session. It is to be hoped that the inclusion of the subject of sibling children at the congress will also raise the profile of the issue within the scientific community and get them “on board”.

Award

SiblingsCLUB wins IBK prize for Prevention and HealthPromotion

The SiblingsCLUB was awarded the International Bodensee Konferenz (International Lake Constance Conference - IBK) prize for Prevention and Health Promotion on 23 April 2013. It was selected from a field of over 150 entries and awarded third prize with prize money of 2,000 EUR. In stating their reasons for their award, the jury highlighted the systematic character of the SiblingsCLUB, pointing out that it operates not just as a single institution, but also within a network of different organisations. Thore Spilger (ISPA) is delighted with the award: “Winning the IBK prize confirms that we are addressing an important issue with our support programme for siblings.”

Information on both SuSi and the SiblingsCLUB can be found at www.ispa-bunterkreis.de/projekt-geschwisterkinder or contact Kerstin Kowalewski (MA) on +49 (0)821 4004922 and Thore Spilger (Dipl. Psychology) on +49 (0)821 4004921.

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