

Working together for siblings



Foto: Fotolia/Sonya Etchison

Editorial

Ladies and Gentlemen,
Dear Friends of FamilyTies,

With the publication of this newsletter we shall be focusing on our forthcoming joint symposium, "Points of access, issues and approaches in working together with siblings". In the meantime, the winners of the second FamilyTies Promotional Award have also been decided and will be announced in Nuremberg on the evening of the symposium on March 16, 2012. We can already stated quite categorically: the standard of the many truly excellent proposals was such that the Advisory Committee found it extraordinarily difficult to select the winners. As usual, we shall describe the winning proposals in detail so that we can all learn from them.

The year also begins with a further good piece of news: Novartis has decided to establish the FamilyTies initiative formally as a Foundation. This means that our efforts to support siblings and their families have now been given permanent form.

Finally, it is now possible to complete the questionnaires and get the results online at LARES Geschwisterkinder. Try it yourself at <http://www.initiative-familienbande.de> (LARES).

We very much look forward to having the opportunity of meeting up with many of you again in person at the symposium in Nuremberg and hope you will enjoy reading this newsletter.

Working together for siblings.



Herlinde Schneider,
Head of FamilyTies,
Novartis Germany



Andreas Podeswik,
Head of ISPA, scientific
cooperation partner

Background

Novartis establishes FamilyTies Foundation

Initiative is put on a sustainable footing



Stiftung
FamilienBande
Gemeinsam für Geschwister

Novartis Germany (in association with Sandoz/HEXAL, Alcon, Consumer Health, Vaccines and Diagnostics) will formally establish the "FamilyTies – Working Together for Siblings" initiative launched in 2010 as a Foundation. The Foundation will continue to take as its principal objective the support of siblings of children who suffer from severe chronic illness or disability and will seek to support them in their particular and often stressful family circumstances. By being granted legal status as a foundation, FamilyTies has now been put on a sustainable footing.

In the words of Mark Never, Chairman of the Board of Novartis Germany and designated Board Member of the Novartis FamilyTies Foundation, the FamilyTies Foundation not only provides greater opportunities for supporting affected sibling children that are more in line with their individual needs but also now ensures that the work done by FamilyTies



The FamilyTies Foundation provides greater opportunities for supporting affected siblings that are more in line with their individual needs – Mark Never, Chairman of the Board of Novartis Germany and designated Board Member of the FamilyTies Foundation

ies in the two previous years can serve as the basis for further development in the future.

Today, FamilyTies already sets great store on using the professional expertise available and on networking with partners who have practical experience in supporting siblings and/or a scientific background. In future, co-operation and partnerships should be developed even further. It is only in this way, according to Mark Never, that this social issue can be managed effectively.

'LARES Geschwisterkinder' now online

The questionnaires for the sibling child/ adolescent and their parents help to communicate the particular stress and the psychological strain the child/adolescent may find himself or herself under. LARES can now also be completed and evaluated by experts online. As with the paper version, the evaluation provides specific help for the different issues: sibling relationships; stress within the family; social integration; school performance; and knowledge about the illness/disability. Go to www.initiative-familienbande.de



LARES Sibling Children:
Easy to complete
online and evaluated
within seconds

Forum

Patron of FamilyTies



Prof. Dr. Karl M. Einhäupl, neurologist und Chairman of the Board of Charité University Medicine, Berlin, is acting as patron of the FamilyTies initiative. In his view, FamilyTies is seeking to address a socially

and medically important issue that is currently not being paid enough attention to in practice. This is the reason why he is giving the initiative his personal support.

When it is not so easy being a child ...

At TEDxBodensee 2011, an independently organised event that aims at disseminating valuable ideas, Christoph Gräf (Head of the Children, Young People and Family Section of the Liebenau Foundation) talked about the problems families with a disabled, severely or chronically ill child are confronted with on a daily basis. The purpose of the talk was to emphasise the need to help affected families from being overwhelmed by the circumstances they find themselves in by offering family-oriented support that takes the child into due consideration. You can see the talk at www.tedxbodensee.de/videos or www.youtube.com

Donation to the Kindergesundheitshaus (House for Children's Health)

On the occasion of the traditional Christmas Market organised by the Novartis companies in Berlin in December 2011, the Neukölln Kindergesundheitshaus received a donation from the FamilyTies initiative. The cheque in the form of a large coin was presented to Petra Grieben und Dr. Thomas Kühn from the Kindergesundheitshaus registered society by Mark Never, Chairman of the Board of Novartis Germany, and Herlinde Schneider, Head of FamilyTies.



Pilot project

The Augsburg pilot project

The Augsburg ISPA Institute, scientific partner of FamilyTies, has launched an initial pilot project to support siblings. The intention is, once everything has been tried and tested, to develop a well-structured concept by 2013 that can be made generally available to other organisations. It is now possible to give a first preliminary result based on the initial events that have been organised.

Getting to a need-oriented approach: animals prove to be a useful support



Siblings help siblings

Two sibling days and a leisure activity have already been organised as Sibling Club events and involving a team of teachers and psychologists looking after numerous sibling children from the Augsburg area. The Supporting Siblings – SUSI – programme, developed in conjunction with the University of Flensburg, is currently underway. Various schemes are now being tested over a period of time and are being developed further following feedback from parents and children.

The carers have a broad range of leisure learning activities open to them. It is the purpose of positive group experiences in particular to enable children and adolescents to cope with the difficulties that may present themselves in the various situations of their daily lives.

The concept is beginning to take shape

Even though many sibling days and leisure activities still lie ahead, cer-

tain key points have already become clear. Caroline Stachura (ISPA) and her team have observed how important it is always to have some form of springboard, such as activities involving animals. The feedback from the initial pilot activities has been distinctly positive. Many children started to talk about specific problems they were having, even spontaneously. Personal contact, above all, is essential for the establishment of any scheme for sibling children. As Caroline Stachura points out, the younger children in particular need the motivation of personal contact to get started.

For further information, contact:

Caroline Stachura (ISPA)
Tel: 0821 400 4922
Email: caroline.stachura@ispa.bunter-kreis.de

FamilyTies Symposium

Our speakers introduce themselves

At the FamilyTies Symposium for Sibling Children in Nuremberg on 16/17 March, speakers from a wide variety of professional backgrounds will present points of access, issues and approaches in their work with siblings. You can get to know some of them a little better today. If you are unable to attend the symposium in person, you will find the talks summarised on the FamilyTies website (www.initiative-familienbande.de) as a follow-up to the symposium.



“What can we learn from Pippi Longstocking?”

Prof. Dr. Klaus Fröhlich-Gildhoff, Lecturer in Clinical Psychology and Developmental Psychology and Head of the Children and Youth Research Centre at the Freiburg Evangelical College, seeks to address the question about what individual and social factors play a role in helping children in particular to be able to cope successfully with crises and stress and possibly even to be able to face up to the challenge as a result.



“Everyone is affected”

Melanie Jagla scientific research assistant in the Department of Health Psychology and Health Education at the University of Flensburg, presents various preventative approaches and a specific scheme providing emotional support and help in developing life-skills in sibling children. As she herself points out, *a chronic illness or disability affects the whole way a family functions, which means there is a need for support from early on.*



“Involvement from the very outset”

Dr. Claudia Ziegler, qualified psychologist in clinical practice and research in general paediatrics at the Kinder- und Jugendkrankenhaus auf der Bult talks about the special features, risks and opportunities in the case of the siblings of children with type 1 diabetes. As she states, *the diagnosis of type 1 diabetes affects the whole family. It is therefore essential to include the siblings of children with type 1 diabetes from the very beginning in discussing how to manage the condition.*



“That is not fair”

Marlies Winkelheide has been supporting the siblings of people with disabilities and illnesses for years in education classes specially designed for the siblings. She learns with and from the siblings. In her talk and in her two workshops she would like to help us to be able to understand clearly what they are trying to tell us. She stresses the importance of *listening to them properly so that we understand what they want to tell us.*



“Targeted support for sibling children”

What can we achieve with ‘LARES Geschwisterkinder’? **Dr. Michael Kusch** (Institute for Health Promotion – IGV Bochum) seeks to answer this question in his talk. As he himself states, *‘LARES Geschwisterkinder’ offers assistance in recognising stress and the psychological strain associated with it in affected sibling children and helps guide children to the help they need.*



“We have a vision”

Andreas Podeswik, qualified psychologist/psychotherapist and Head of the Institute for Social Medicine in Paediatrics, Augsburg (ISPA), will explain the current status of the FamilyTies initiative together with Caroline Stachura. He states that *they have a vision of uniform, quality-assured support for siblings tailored to individual need. To this end, they have developed and will develop targeted assistance and support schemes in conjunction with professionals in the field of sibling support.*



Recommended books

by Marlies Winkelheide

In the eyes of the others

Jodi Picoult

This extraordinarily gripping book describes a mother grappling with the question whether her autistic son might have killed someone. It describes the battle the mother has gaining the trust of others in her children, in their recognition of someone being different, of a "special normality". If you read the book from the perspective of the brother who is not affected, you experience touching thoughts, ambivalent feelings and subconscious expectations.



Wednesdays or "Let's get out of here", says Auntie Hulda

Sylvia Heinlein

Sara's Auntie Hulda lives in a home as she has a disability. Sara goes to visit her there every Wednesday. Her aunt doesn't want to move to another home, and Sara helps her to escape. An interesting and gripping children's book (suitable for children from the age of 10), which describes life with a disability very sensitively. The reader learns a lot about the unusual relationship between two sisters in the course of their lives, about the special relationship between niece and aunt and the unique experiences on those Wednesdays.



STARK – the Lebenshilfe Main-Taunus remedial advisory support centre and registered society

STARK (strong) counselling for families

They listen to me, have done a lot for us and are patient and totally committed - such is the positive feedback to what the Lebenshilfe Main-Taunus advisory support centre has to offer.



They are strong. I get support there. I feel really good there. These are some of the comments from parents and young people who have made use of the support and advice offered by STARK.

At STARK, people with a disability and their families from the Main-Taunus area can seek solutions together and find answers to an incredible variety of questions and challenges.

Help – everything centres around my brother/sister!

How can I explain the disability of my one child to my other child? What offers are open to siblings? Where can we get support as a family? Families come to STARK with these and other issues.

To ensure that siblings and their families are not left alone to cope with these issues, the advisory centre offers a range of support options, such as information sessions, courses for parents, breakfast for parents and two reading groups for young people with a disability. Families can also use the individual counselling service, which is free of charge, over longer periods of time.

Exchange of views across the generations

Last year in an information session,

siblings, parents and professionals representing all ages exchanged experiences and developed strategies to deal with the many challenges that affect siblings, such as offering age-appropriate explanations, space for worries, fears and needs, self-help groups, sibling seminars and offers of counselling or "mum" time.

Rebekka Junghans,
Head of the STARK
support centre



Key information

STARK – Main-Taunus remedial advisory support centre and registered society

Gegründet: 2009

Support for siblings:

Advice and support, information sessions, information about events for sibling children

Participants:

People with a disability and their families

Address:

Kurhausstraße 11
65719 Hofheim am Taunus
www.lebenshilfe-main-taunus.de
Email: beratungsstelle@lhmtk.de
Tel.: 06192 95 86 42-0 –
Rebekka Junghans



FamilyTies
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Imprint

Content: FamilyTies network

Editing and realisation: Elke Hellstern,
Healthy Communication, Munich

Publisher: FamilyTies, Herlinde Schneider,
Novartis Germany GmbH, Nuremberg Office,
Roonstr. 25, 90429 Nuremberg

We value your opinion

Please tell us what you liked about the FamilyTies AKTUELL newsletter or what could be improved. If you are not interested in receiving the newsletter, please contact us at
info@initiative-familienbande.de