

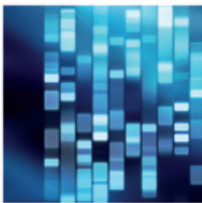


SANFILIPPO
FOUNDATION
Switzerland



Michelle Calmy-Rey,
Foundation Sponsor

© Philippe Christin



January 2010

Thank you for supporting the efforts of the Foundation and giving a glimmer of hope to all the families of sick children.

DONATIONS: CCP n° 10-185368-3

Sanfilippo Foundation Switzerland



Nonprofit Foundation

A Word from the President of the Sanfilippo Foundation Switzerland



Frédéric and Stéphanie Morel

Here we are! It's already been one year, and the Foundation has raised 480,000 Francs, funded three promising research programmes, and hosted our first Gala with 280 guests in attendance. This first year was a busy one, and thanks to you, we are maintaining the enthusiasm of our beginning as well as our will to find a treatment for this terrible childhood disease. With such strong momentum behind us, we will not slow down. And we are counting on you in 2010, because together we will be able to conquer this disease.

Once again, thank you so much to all of you, and we extend all our wishes of hope and happiness for the New Year 2010.

*Frédéric Morel, father of Charlotte (5 years old)
President of the Foundation's Board*

The Foundation's first Gala Event Sunday, November 8, 2009

On Sunday, November 8, 2009, the Beau-Rivage Hotel hosted more than 280 people attending our first Gala, presented by Lolita Morena and featuring children of all ages, whether they are sick or not, on stage for a stunning fashion show, supervised by CdeC (Cordelia de Castellane).



from left to right, Olga Saillard, Lolita Morena (Hostess of the Gala)

© Shootingdéluxe.com



Charlotte Morel at the fashion show

© Enzo Capaccio

It was an afternoon, dedicated to children and supported by Naef and Company and Hinduja Bank, that allowed us to collect nearly 70,000 Francs in order to support research programmes selected by the Scientific Committee of the Foundation.

After the fashion show, the auction conducted by Caroline Lang of Sotheby's, and including magnificent items such as a tennis racket signed by Roger Federer and a trip donated by Alinghi and presented by Mrs. Kirsty Bertarelli, greatly contributed to the funds gathered by the event.



from left to right Frédéric Morel (President of the Sanfilippo Foundation), Countess Massimiliano Secco d'Aragona

© Enzo Capaccio

Support for the creation of a Swiss Alliance for the Care of Rare Diseases

Over the year 2009, the Sanfilippo Foundation Switzerland was also committed to supporting the creation of an Alliance for the Care of Rare Diseases. This central agency will have as its mission the assembly of associations and foundations in Switzerland which address issues related to rare diseases, but also to represent families affected by this type of illness. The creation of this Alliance is crucial, given that in Switzerland nearly 500,000 people are affected by a rare disease.

We are happy to announce that the Alliance of Rare Diseases is scheduled for inauguration on the 3rd International Rare Diseases Day, February 28, 2010.

Our involvement in developing a world platform for the Sanfilippo Families



The members of the Foundation are also in close contact with Eurordis, in particular in order to launch a website enabling families of children affected by Sanfilippo Syndrome to exchange information and advice and also to search for information on the disease and current efforts.

This site has been launched in pilot form, as Sanfilippo Syndrome was not chosen at random. Indeed, thanks to the families, we have been able to show our real determination and that is the reason why Sanfilippo Syndrome will be one of the first diseases to benefit from this exceptional communications tool.

To ensure its success, we call on all the families to share with us their ideas on topics that should be addressed:
info@fondation-sanfilippo.ch

Poster Campaign on the Tramways of Geneva

In order to make a larger and larger public aware of the problem of rare diseases, we have created, as you may be aware, a poster campaign on the public transport network of Geneva. We would be pleased to hear your impressions on this, our first campaign, on :

info@fondation-sanfilippo.ch



2010 Activities – Objectives

The objectives for the year 2010 are clear: to continue to gather funds to allow us to carry on with activities undertaken in 2009 by the Foundation, but also to be able to support the programmes of promising supplemental research.

What's more, we are taking advantage of this informational bulletin to inform you that in 2010 we are going to renew our Call for Proposals.

Priority will however be given next year to research programmes emanating from Swiss researchers.

Our role as providers and disseminators of information for families is one of our beacon activities and to assist us in this, we invite you to consult our internet site regularly: *www.fondation-sanfilippo.ch*.

It should be noted that the site was visited some 50,000 times in 2009, and to us it seems vital to provide regular updates.

2009 Activities – Retrospective

First call for proposals in January 2009: after the meeting of the Scientific Committee of the Foundation, three promising programmes were selected and are receiving ongoing support from the Foundation.

Conception of chemical chaperones

Conception and evaluation of new chemical chaperones of the N-acetylglucosaminidase in the context of the development of a treatment for Sanfilippo Syndrome (MPS III B).

This research and development project, organized by the team of Professor Matthieu Sollogoub (CNRS / UMR, Université Pierre and Marie Curie, Paris), consists of developing glycosidic inhibitors of the N-acetylglucosaminidase.

It is expected that these new molecules will be able to correct the structure and intracellular transport of certain mutated forms of the N-acetylglucosaminidase and therefore restore the ability to degrade heparan sulfate.

The total budget of nearly 300,000 Euros will be used initially for the development of the method of production of these new glycosidic structures.

In the next stage, funding will be devoted to evaluating these molecules in the cellular in-vitro models of the disease.

It should be noted that the Foundation has taken appropriate measures to protect intellectual property (patents) issuing from the work it finances.



Bone Marrow Grafting



Dr. Lau

After our Call for Proposals launched in early 2009 with the goal of supporting programmes of promising research for children stricken with mucopolysaccharidosis (MPS), the Foundation selected the project of Dr. Adeline Lau (Adelaide, Australia) who has been working for several years on this disease.

Dr. Lau's thesis director is Dr. John Hopwood, a widely-recognized specialist in this field.

This research consists of continuing work already begun on repopulating the central nervous system by cells derived from bone marrow grafting. The goal of this study is first to establish a grafting procedure, and then to verify if the transfer of the marrow is beneficial on mice afflicted with MPS. It should be noted that this technique does not stem from gene therapy.

Gene Therapy

The trial on gene therapy for MPS III A children organized by the Sanfilippo Alliance and supported by the Foundation should begin in September 2010, with 4 children aged between 2 and 5 years old. Currently in the toxicological study phase, authorizations should be obtained by early 2010.

Partnerships / assistance provided by:

A tremendous thanks to all of you for your precious support. Thanks to you, we are advancing research on these forgotten diseases, and together we will be able to conquer this terrible illness affecting our children.

A tremendous thank you too to our guardian angels including in particular:



Mrs. Micheline Calmy-Rey

© Philippe Christin

Mrs. Micheline Calmy-Rey

The Alfred and Eugénie Baur Foundation Mr. Olivier Dunant

Kiwaniis Lake Geneva Ecurie De la Meute

NAEF & Company Hinduja Bank

Rotaract of Geneva Michelham Foundation

Swiss Telethon AEMO

Rotary Club of Bellegarde (France) Rotary Club Lake Geneva



The testimonial of Joséphine's parents



Joséphine

Joséphine is our first child. We waited and wanted her for 3 years. Until this unforgettable date, February 21, 2008, everything went wonderfully well. When the time came for our little darling's two-year checkup, the pediatrician to whom we had communicated her trouble maintaining balance asked us to hospitalize Joséphine for a day for a series of tests.

This was to erase doubts about a diagnosis of retardation...A week later, we received the verdict that changed our lives. Joséphine was suffering from a very rare, dramatic and incurable disease, MPS III.

Our world crumbled. The ground disappeared beneath us and we couldn't even breathe. Suddenly a question jumped to mind: "Doctor, what about the new baby we have been expecting for July? Will he also be sick?" The odds are 1 in 4 that this child will also be afflicted. We were a family that had never been faced with any serious crisis, and we had everything to make us happy. We thought, selfishly, that things like this "only happen to other people." Now life was attacking what we had that was most precious to us, what was most dear, and what we loved with an immeasurable devotion: our children! Quite fortunately, on March 19, a ray of sunlight came once again to brighten our days: our son was born, unafflicted by Sanfilippo Syndrome. Since then, we have learned to live with the knowledge that our daughter is sick. Our son Nathanael was born on June 15. And we want to believe that our Joséphine will overcome the disease.

Upcoming Events

28 February, 2010 International Rare Diseases Day

May/June 2010 Vehicle Assembly organized by Rotary and Ecurie De la Meute

November 2010 2nd Gala of the Sanfilippo Foundation Switzerland

June 2010 Next Newsletter

The members of the Foundation are at your service to provide further assistance: info@fondation-sanfilippo.ch

