

# PROGRAMME

10-13TH OCTOBER 2014 DISNEYLAND PARIS, FRANCE

## 2nd European Tay-Sachs & Sandhoff Disease Family Conference

One goal. One group. One voice.

Organised by



With the support of



*Vaincre le Tay-Sachs*

The European Tay-Sachs Charity Consortium (ETSCC) provides a unified voice in the fight against Tay-Sachs and Sandhoff disease - [etscc.org](http://etscc.org)



# Welcome to the 2nd European Family Conference

“On behalf of everyone involved with the conference and the European Tay-Sachs Charity Consortium (ETSCC), I am delighted to welcome you to the 2nd European Tay-Sachs and Sandhoff Disease Family Conference at Disneyland Paris.

After the success of the first family conference held in Mondsee, Austria in 2013 we wanted to ensure that all the families in Europe would have the opportunity to meet together once a year. We believe that this is vital as it allows us all to discuss treatments, coping with the diseases and to make new friendships.



Over the weekend we have planned sessions to enable us to discuss the progress of the research into the diseases and also the day to day management of caring for a child affected by the diseases.

Sadly, there are some families who have been unable to attend as their children are not well enough to travel long distances. We would like to express our gratitude to their support and they remain in our thoughts.

Lastly, I look forward to catching up with everyone at some point during the weekend and I hope you enjoy not only the conference, but Disneyland Paris as well!”

A handwritten signature in black ink, enclosed in a hand-drawn oval. The signature appears to be 'D. Lewi'.

Daniel Lewi

Chairman of the European Tay-Sachs Charity Consortium (ETSCC) and Co-Founder of The Cure & Action for Tay-Sachs (CATS) Foundation

# Conference program – Saturday 11th October 2014

On the first day of the 2nd European Tay-Sachs and Sandhoff Disease Family Conference we will have introductions to the various charity members of the ETSCC as well as an update on the research into a potential treatment. In the afternoon we will hold two group discussions on topics that have affected various families.

Session time	Session details
<b>09:30 - 10:00</b>	<b>Arrival and registration</b>
10:00 - 10:10	Introduction to the conference Daniel Lewi, Chairman of the ETSCC
10:10 - 10:30	Update about Hand in Hand gegen Tay-Sachs Eva Irran, Chairperson of Hand in Hand gegen Tay-Sachs
10:30 - 10:50	Introduction on ACTAYS Beatriz Fernandez, Founder of ACTAYS
10:50 - 11:10	Update on The Cure & Action for Tay-Sachs (CATS) Foundation Daniel Lewi, Co-founder of The CATS Foundation
11:10 - 11:30	Introduction on Vaincre le Tay-Sachs Ozcan, Founder of Vaincre le Tay-Sachs
<b>11:30 - 11:45</b>	<b>Coffee break</b>
11:45 - 13:00	Research update Professor Timothy Cox, Cambridge University
<b>13:00 - 14:30</b>	<b>Lunch</b>
14:30 - 14:40	Morning summary and afternoon introduction Daniel Lewi, Chairman of the ETSCC
14:40 - 15:10	Q & A session about research Session chair – Daniel Lewi
15:10 - 16:00	Group discussion on symptom management Session chair – James Alford
<b>16:00 - 16:30</b>	<b>Coffee break</b>
16:30 - 17:30	Group discussion on dealing with family issues Session chair – Beatriz Fernandez
17:30 - 18:00	Questions on the day's discussion topics Session chair – Daniel Lewi

## Conference program – Sunday 12th October 2014

On the second day of the 2nd European Tay-Sachs and Sandhoff Disease Family Conference we will hold various workshops that each family can get involved with. All of these workshops have been designed to help everyone gain an understanding of different topics which they may encounter when caring for an individual affected by the diseases.

Session time	Session details
<b>09:30 - 10:00</b>	<b>Arrival</b>
10:00 - 11:15	Workshop 1 – Breathing therapy Workshop leader – Eva Irtan
<b>11:15 - 11:45</b>	<b>Coffee break</b>
11:45 - 13:00	Workshop 2 – Making memories & photography session Workshop leader – Eva Irtan
<b>13:00 - 14:30</b>	<b>Lunch</b>
14:30 - 15:45	Workshop 3 – Family interviews & photography session (continued) Workshop leader – Daniel Lewi
<b>15:45 - 16:15</b>	<b>Coffee break</b>
16:15 - 17:30	Remembrance ceremony Led by Nikki Backus

## Disney's Sequoia Lodge - the hotel

Everyone attending the conference is staying at the Sequoia Lodge hotel which can be found at the point mark with the number three on the map below. The conference itself is taking place at the Newport Bay Hotel which is marked with the number four in the map below.

As we are all booked into the Golden Forest rooms at the Sequoia Lodge hotel it means we have access to many extra facilities as well as the normal benefits of staying at the hotel. The facilities we will all have access to are:

- Heated indoor swimming pool
- Two restaurants and one bar
- Access to the Golden Forest private lounge for breakfast
- Free afternoon and evening snacks plus hot drinks in the Golden Forest private lounge
- Hotel address – Disney's Sequoia Lodge, Avenue Robert Schuman, 77700 Coupvray, France
- Hotel telephone number – +33 1 60 45 51 00

The hotel is conveniently located a short walk from the convention center, the Disneyland Village and the Disney Parks. We plan for all of us to visit and enjoy the parks when the conference presentations have been completed.



## Disney's Newport Bay Club - the conference center

The 2nd European Tay-Sachs and Sandhoff Disease family conference presentations will take place at Disney's Newport Bay Club Convention Center. This hotel is a short five minute walk from Disney's Sequoia Lodge hotel where we are all staying.

The conference room will be used by us all for the planned two days of presentations on the 11th and the 12th October. There will be a variety of facilities available to us during the conference, which will include:

- Tea and coffee
- Cakes and biscuits
- Soft drinks
- Lunch service
- Access to disabled toilets
- Private room

As the conference is taking place in another hotel we ask that you arrive before the start of each session. Unfortunately, we have a lot of presentations planned over the two days and we will not be able to delay the start of each session so if you are late you will miss the beginning of each one.



## Disneyland Paris - what to do

Share magical family moments at the place that's so much more than a theme park. Alive with Disney magic all year round, there's always something unforgettable for the amazement of all ages.

Two Disney Theme Parks teem with more than 50 rides and attractions while Disney shows and parades offer endless entertainment, including seasonal spectaculars. Plus, with Disney Village bustling nearby and sightseeing in Paris and the surrounding region right on your doorstep, you can experience it all at Disneyland Paris theme parks today.

### Disneyland Park

At Disneyland Park, fairytales take flight across five incredible lands – from the pirate-filled waters of Adventureland to the Wild West of Frontierland. Experience your favourite Disney stories coming to life before your very eyes and discover how dreams come true every day in this part of Disneyland Paris.



### Walt Disney Studios Park



Walt Disney Studios Park is the place to discover the secrets of Disney animation. From legendary moments in motion at Toon Studio to the mind-boggling effects of the Backlot, its five production zones are focused on fun for stars of all sizes. With lots to learn about television and movie magic and plenty of ways for everyone to enjoy time in the limelight.

### Disney Village

Discover fun around the clock – and even up in the air – at Disney Village, an entertainment district that's like no other. Starting at the Disney Park gates and going until late with its cinema, shopping, restaurants, dancing and shows for the whole family, there's even your chance to catch Buffalo Bill's Wild West Show... with Mickey and Friends.

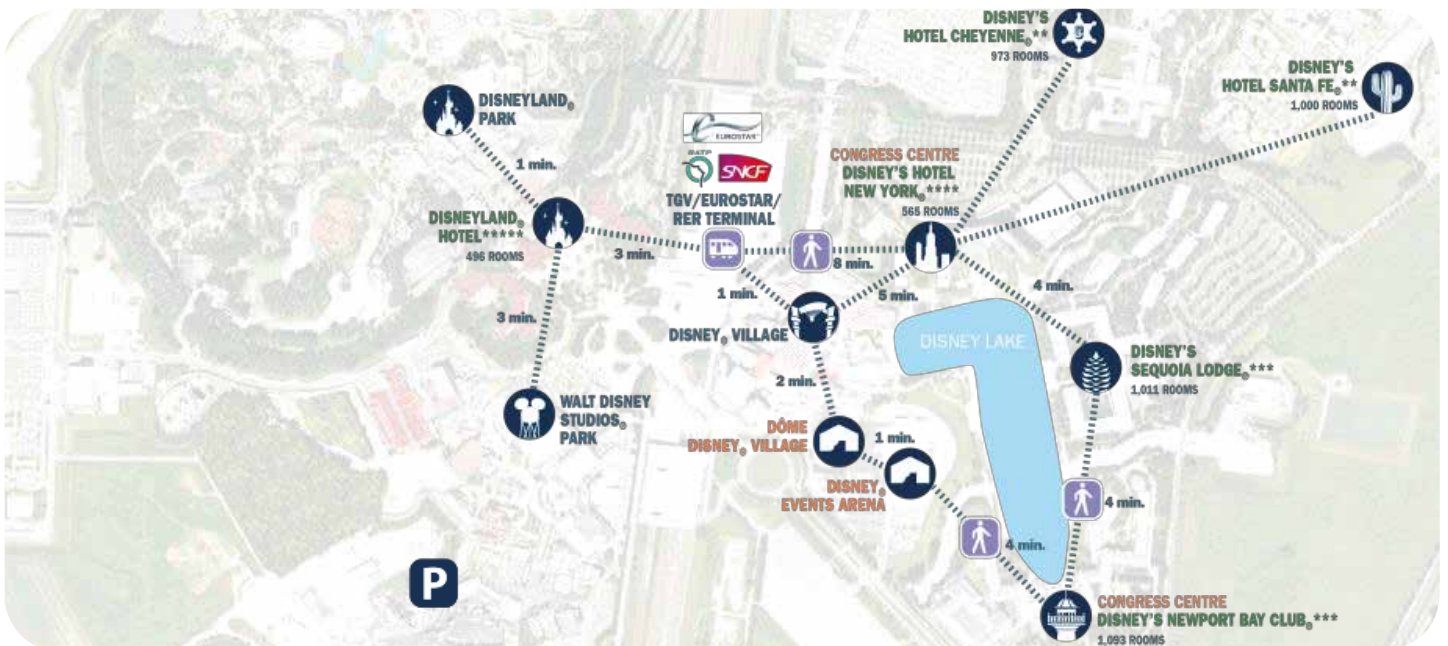




# Disneyland Paris map



**Key:** 1 – Disneyland Hotel; 2 – Disney's New York Hotel; 3 – Disney's Sequoia Lodge Hotel; 4 – Disney's Newport Bay Club Hotel; 5 – Disney's Santa Fe Hotel; 6 – Disney's Cheyenne Hotel



**Note:** All walking distances are estimated

## 1st European family conference review

“On the 28th September, it finally happened! After months of planning and organising we, a family from Austria, England, Slovenia and Spain checked in together at the hotel Eichingerbauer in Mondsee, Austria and had a wonderful dinner together. The first European Family Conference was underway and we even had the pleasure of Professor Cox joining us for dinner.



The next day we started with our most important day of the conference, the lecture day. Daniel opened this interesting day with his presentations of The CATS Foundation and the ETSCC (European Tay-Sachs Charity Consortium). After Dan's lecture we had the opportunity to listen to one of the most important lectures of the weekend, Professor Cox's talk about the Tay-Sachs and Sandhoff research in England and we were given an insight into his team's work on gene therapy.

After the research, Dr. Spona from Vienna gave his very interesting presentation on amino acids and why they are so important. After lunch, we then enjoyed a presentation by Dr. Lagler who is a metabolic specialist from Salzburg. This talk was titled “From the idea to the drug,” and explained the long and arduous road to getting a medical drug on the market.

After Dr. Lagler, it was my turn and I gave a presentation about our association and afterwards we watched a video of an interview with Jürgen Lueger, Bioenergethiker about alternative medicine. We then had a very helpful discussion together, where we were able to share our personal recommendations about many things related to caring for a child affected by Tay-Sachs or Sandhoff disease. With a fantastic dinner at the restaurant of the Countryhotel Eichingerbauer we were able to complete the first conference day.

On the Monday we started the “Creating Memories Workshop” which was created in collaboration with Nadja Leeb whose beautiful artwork we will forever be a unique reminder of this event and of our children. We made fantastic family photos with the wonderful photographer Afra Hämmerle Loidl



## 1st European family conference review

and in the afternoon we celebrated the life of our angels in heaven, by honouring them with the "Candle Lighting Ceremony" where we were accompanied by pastor Wageneder. To finish this day we sent colorful balloons in the sky to all the children who have already lost their fight.

Tuesday was the last day for our families and we used the last hours together to get a little insight of the spiritual healing work of Claudia, and to complete our artworks. I was moved to tears when Zivan and myself were given each a voucher for a massage as a thank you for the planning the family conference. This showed us how great the event was for everyone who attended, and how closely we had grown together. These friendships are very special in my eyes, because no one else in the world can really understand how you feel and how life is with a child suffering from Tay-Sachs or Sandhoff. Only those families can and only with them is it ok to laugh and cry because they truly understand. Together, no explanations were necessary and we all cried together, laughed together, are proud of each other and we all love each other's children as if they were our own. We are all a family, and although it is one in which you never would have wanted to be part of, we are all eternally grateful to have."

Eva Irran

Chairperson of Hand in Hand gegen Tay-Sachs



## Session details – Saturday 11th October 2014

10:00 – 10:10

Introduction to the family conference



Now in its second year, the European family conference aims to bring families together to discuss the challenges of caring for a loved one affected by these diseases. This short introduction will provide overview for the morning session which focuses on the charity members of the ETSCC.

Daniel Lewi, Chairman of the ETSCC

Update on Hand in Hand gegen Tay-Sachs

10:10 – 10:30

Hand in Hand against Tay-Sachs was founded in August 2012 one year after my daughter Haylie was diagnosed with Tay-Sachs Disease. In Austria and the whole German speaking world there was no association for the disease and the only information, including the research, was in English.

Understanding medical terminology in English when it is not your first language is very hard so I decided to change that. The association was created to support European Families, with a focus on the German speaking world. We are also one of the founder members of the ETSCC and I am the vice chairperson of the consortium.

Eva Iran, Chairperson of Hand in Hand gegen Tay-Sachs



## Session details – Saturday 11th October 2014



Introduction on ACTAYS

10:30 – 10:50

We launched Acción y Cura para Tay-Sachs (ACTAYS) in Spain during 2014 after realising there was very little information about Tay-Sachs in Spanish. ACTAYS was created under the spirit of getting all these families in touch, to share experiences, knowledge about the different specialist medical centers in our country and to translate information into Spanish. We were recently accepted to become a member of the ETSCC.

Beatriz Fernandez, Founder of ACTAYS

10:50 – 11:10

Update on The Cure & Action for Tay-Sachs (CATS) Foundation

The CATS Foundation has grown in strength in the last year and we have expanded our support of families. We are now able to provide equipment, support and respite trips to families which has had a significant benefit to our member families. In addition, we have received various grants to create educational materials.

Our role with the research team has continued to increase and we are looking forward to getting more involved in this work in the next year.

Daniel Lewi, Co-founder of The CATS Foundation



## Session details – Saturday 11th October 2014

11:10 – 11:30

Introduction on Vaincre le Tay-Sachs



Vaincre le Tay-Sachs was created as a non-profit to help the families of those who have children affected by Tay-Sachs and Sandhoff disease in France. The priority of the association is to raise funds and to invest in the research for a potential treatment.

Ozcan Altinkaynak, Founder of Vaincre le Tay-Sachs

Update on the research

11:45 – 13:00

The work into a gene therapy trial for Tay-Sachs and Sandhoff disease (GM2 Gangliosidosis) being undertaken in Cambridge has steadily been progressing. Several significant steps have been achieved since the team was awarded its grant of £2.84 million from the UK Medical Research Council (MRC) for the trial and each day brings us closer to achieving our goal of having a treatment for these diseases.

The team remains pretty well on course for starting the clinical trial in the next two to three years. This will bring some hope and comfort to families affected that there is continuing activity in Europe towards the development of potential new treatment.

Professor Timothy Cox, Addenbrooke's Hospital & Cambridge University



## Session details – Saturday 11th October 2014



Morning summary and afternoon introduction

14:30 – 14:40

After an interesting morning of charity and research updates I will provide a short review of what was discussed. This will give everyone the opportunity to ask any questions which will then be followed by an introduction to the afternoon session.

Daniel Lewi, Chairman of the ETSCC

14:40 – 15:10

Q & A session about research

After an interesting presentation by Professor Cox regarding the research into a potential treatment for Tay-Sachs and Sandhoff disease there will be the opportunity to ask questions about the work being undertaken.

During this session we ask that only information about the research be discussed and we will not accept questions regarding the cases of individual children, selection criteria for the trial and national healthcare systems.

Session chair – Daniel Lewi



## Session details – Saturday 11th October 2014

15:10 – 16:00

Group discussion on symptom management



Managing the many symptoms of Tay-Sachs and Sandhoff disease is one of the biggest challenges for a carer. The main goal for this type of treatment is to make the individual's quality of life as high as possible, which is why sharing and discussing our own experiences, is vital. We will be able to share ideas and tips which could be valuable to other families.

During this session we would like everyone to speak freely and openly and I manage the session to ensure we stay on topic.

Session chair – James Alford

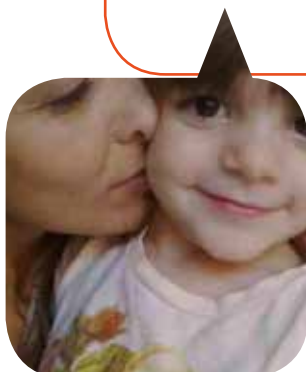
Group discussion on dealing with family issues

16:30 – 17:30

Coping with a diagnosis of Tay-Sachs or Sandhoff disease within a family can be very challenging. Some family members find it very difficult to accept that their loved one is affected by a terminal illness and this can cause problems.

During this session we will discuss how important family dynamics are and how a positive environment can have a positive impact on a family. We ask you not to share what was talked about to those who were not present.

Session chair – Beatriz Fernandez





## Session details – Saturday 11th October 2014



Questions on the days discussion topics

17:30 – 18:00

A summary session will be held where we can all discuss what was presented during the first day of the conference. This will give everyone the opportunity to ask any other questions which they may have about any of the subjects discussed.

Daniel Lewi, Chairman of the ETSCC

## Session details – Sunday 12th October 2014

10:00 – 11:15

### Workshop 1 – Breathing therapy



The first workshop will give us all an opportunity to learn about various massage techniques to help the children with their breathing. All of these have been demonstrated to me via a physiotherapist and can have a positive impact on breathing.

Workshop leader – Eva Irran

### Workshop 2 – Making memories

11:45 – 13:00

The making memories workshop will be very similar to what we did last year, where everyone will have the opportunity to make a variety of items. Everyone is welcome to experiment with all the different materials which will be available.

Workshop leader – Eva Irran



## Session details – Saturday 11th October 2014



### Workshop 3 – Family interviews

14:30 – 15:45

As part of a project for The CATS Foundation we plan to hold short interviews with families where we will discuss a list of frequently asked questions that people have after a loved one has been diagnosed with Tay-Sachs or Sandhoff disease. Each of these interviews will last 10 minutes and will be sent to the families once they have been edited.

Workshop leader – Daniel Lewi

16:15 – 17:30

### Remembrance ceremony

To complete the two days of presentations we will hold a remembrance ceremony for all the children who have lost their battle against Tay-Sachs and Sandhoff disease.

Afterwards, there will be a chance for us all to reflect on what has been discussed and to ask any final questions.

Led by – Nikki Backus



## List of participants

First name	Last name	Country
Amelie	Durao Lewi	England
Patricia	Durao Lewi	England
Daniel	Lewi	England
Grace	Durao Lewi	England
Isabella	Alford	England
Deborah	Alford	England
James	Alford	England
Nikki	Backus	England
Sam	Backus	England
Ruby	Shone	England
Hope	Crane	England
Sally	Crane	England
Tracey	Crane	England
Liam	Qvarforth	Sweden
Madeleine	Qvarforth	Sweden
Rebecca	Tingvall	Sweden
Rodrigo	Mendoza Samper	Spain
Ainhoa	Samper Ruera	Spain
Ricardo	Mendoza Durán	Spain
Yago	Mendoza Samper	Spain
Sergio	Roque Buitrago	Spain
Rosa	Buitrago Rodriguez	Spain
Juan Carlos	Roque Garcia	Spain
Isabel	Rodríguez Fernández	Spain
Beatriz	Fernández Domínguez	Spain
Martín	Rodríguez Yebra	Spain
Haylie	Irran	Austria
Eva	Irran	Austria
Zivan	Basic	Austria
Afra	Hämmerle-Loidl	Austria
Dario	Hardt	Germany
Birgit	Hardt	Germany
Folker	Quack	Germany
Dalya	Altinkaynak	France
Ozlem	Altinkaynak	France
Ozcan	Altinkaynak	France
Tim	Cox	England
Jenny	Lewi	England
Katy	Lewi	England



Your notes



The European Tay-Sachs Charity Consortium (ETSCC) provides a unified voice against Tay-Sachs and Sandhoff disease. For more information please visit [etscc.org](https://etscc.org).