

01 December 2022 - 02 December 2022

9TH EUROPEAN TAY-SACHS & SANDHOFF FAMILY CONFERENCE



SUPPORTED BY

[azafaros](#)



[sanofi](#)

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The full agenda of the 9th European Tay-Sachs and Sandhoff Family Conference is below, and you can watch each of the presentations given by our speakers over the two days on YouTube via the summary page for each talk

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EUROPEAN TAY-SACHS & SANDHOFF CHARITY CONSORTIUM (ETSCC)

The ETSCC was established in 2013 to enable European charities to come together in the fight against Tay-Sachs and Sandhoff. The member charities are from the United Kingdom, Spain, France, Germany and Portugal.

All of the patient advocacy groups who are members of the consortium are recognised charities in their country of origin. The three aims of the ETSCC are to raise awareness of Tay-Sachs and Sandhoff, support the research for a potential treatment and provide a united European voice. The members of the ETSCC meet once a year to discuss the progress of the research into Tay-Sachs and Sandhoff and the consortiums strategy.

The members of the ETSCC are The Cure & Action for Tay-Sachs (CATS) Foundation based in the UK; Acción y Cura para Tay-Sachs (ACTAYS) based in Spain; Vaincre Les Maladies Lysosomales (VML) based in France; Hand in Hand gegen Tay-Sachs und Sandhoff based in Germany; and Divulgar e Orientar para Combater e Enfrentar a Tay Sachs, Sandhoff e GM1 (DOCE) based in Portugal.

The ETSCC was formed to give a European voice to patients, families and charities battling to find a cure for Tay-Sachs and Sandhoff disease. We do this by:

RAISING AWARENESS - Members of the ETSCC are all dedicated to raising awareness and creating a deeper understanding of Tay-Sachs and Sandhoff disease.

SUPPORTING RESEARCH - The ETSCC supports the research into Tay-Sachs and Sandhoff and helps drive forward these projects so a cure can be found.

UNIFIED VOICE - As a collective, the ETSCC allows for country specific charities supporting Tay-Sachs and Sandhoff have a unified voice against the diseases.



ETSCC CHARITIES WHO PARTICIPATED IN THE CONFERENCE



THE CONFERENCE

The 9th European Tay-Sachs and Sandhoff Family Conference is the second event we have held online to bring together all our families and partners to hear about the latest work into supporting our community

In Europe we have worked hard at bringing Tay-Sachs and Sandhoff families together so that they have access to information and support. Through the ETSCC we have been holding annual family conferences with the intention to provide a forum for discussion about topics that can support the care of someone affected by the diseases, to hear updates on the latest research into treatments and enable families to meet each other in person.

The first event was held in Mondsee in Austria in 2013 and was attended by four families. This event was the start of something which has grown year on year and we have held events in London, Madrid, Paris and Wurzburg. However, due to the COVID crisis that has impacted the entire world we were forced to shift how these events have been held. Instead of an in-person conference where families have been able to meet, we had to move online for the last two years.

After the success of last year's virtual conference, we were delighted that in 2022 we were able to hold our 9th European Tay-Sachs and Sandhoff Family Conference. Utilising the digital format, we have been

able to reach more families who could not travel to an in-person event. In addition to this, we have been able to secure speakers from various companies who may have not been able to attend a live conference.

We are aware that the in-person conference is preferable to our families. We also know that a digital version makes it accessible to more people, so we are planning on changing the format on how our Family Conferences are held in the future. Starting in 2023, we plan to hold an in-person event every two years in the Spring / Summertime which will have a focus on families meeting and learning about caring for someone impacted by Tay-Sachs and Sandhoff. In addition to this, we plan to hold an annual virtual conference in November / December of each year to hear summary talks from industry and new projects being launched by advocacy groups.

We hope that this new format will enable us to continue our reach of support to families whilst also giving our industry and advocacy partners the opportunity to continue working with our very special community all year around.

LYNN EASDALE - MUM TO JAYDEN

"To hear about the latest research into the diseases was brilliant as we are getting closer and closer to a treatment. I really enjoyed the virtual format but I can't wait for us to be able to join an in-person conference in the future!"

GISELA LINTHORST - AZAFAROS

"Supporting the patient community is important for Azafaros as we believe that a close collaboration in support and empowerment with patient groups can be crucial in advocating and changing the lives of patients and their families."

The agenda for the 9th European Tay-Sachs and Sandhoff Family Conference was developed based on ensuring that we covered topics that were of value to our community. We wanted to ensure that there was the opportunity for our families to learn about projects that have been launched for Tay-Sachs and Sandhoff disease whilst hearing the latest research updates. We achieved this by continuing to split the conference over two days, where each day has a specific focus.

Day one covered the topic of adherence to clinical trials and how this can be addressed with health information that has been created for patients and their families. This day also contained talks about how families can access information on Tay-Sachs and Sandhoff. The second day of the conference focussed on the research and current studies for Tay-Sachs and Sandhoff along with the work that is being done to develop a truly global movement for our community.

Family Conference
VIRTUAL EVENT
01 - 02 December 2022
9th European Tay-Sachs & Sandhoff Family Conference

JOIN US

Each day will start at 13:00 GMT and finish at 16:00 GMT

ETSCC
EUROPEAN
TAY-SACHS
CHARITY
CONSORTIUM

ACTAYS
DOCE

[VISIT THE CONFERENCE WEBSITE](#)

THE 9TH EUROPEAN TAY-SACHS AND SANDHOFF FAMILY CONFERENCE WAS HELD USING THE HOPIN TECHNOLOGY WHICH ALLOWED US TO REACH AN AUDIENCE ALL OVER THE WORLD

Every year we are very grateful to all the speakers and companies who agree to attend and present at the conference. They all generously give up their time to provide updates on their work and detail how this is impacting the Tay-Sachs and Sandhoff community. We also want to say a big thank you to Azafaros, JCR Pharmaceuticals and Sanofi who all sponsored the 9th European Tay-Sachs and Sandhoff Family Conference. Their support was vital in enabling us to hold the event in 2022.



38%

PARENT, CARER AND PATIENT PARTICIPANTS

Attendees from this group were from 15 different countries.

26%

INDUSTRY PARTICIPANTS

Nine different industry companies were in attendance.

16%

ADVOCACY PARTICIPANTS

Attendees from ten different advocacy groups joined the conference.

13%

CLINICIAN PARTICIPANTS

Clinicians from five countries joined the event.

6%

RESEARCHER PARTICIPANTS

Researchers based in the US and Europe attended the conference.



18 PRESENTATIONS 3 PANEL DISCUSSIONS

REGIONAL SPLIT OF CONFERENCE PARTICIPANTS

Europe	70%
North America	19%
Asia	4%
South America	3%
Australasia	2%
Middle East	2%



Follow this Tip:

Do you want to read the complete report? This will be available on the ETSCC website alongside summaries of other conferences.

[CLICK HERE TO READ THE EVENT SUMMARY FROM ALL OUR CONFERENCES](#)

DAY 1

INTRODUCTION

As more of the research for Tay-Sachs and Sandhoff moves forward with clinical trials, it is important for the community to understand why adhering to a clinical study is so important and the impact it can have on the community

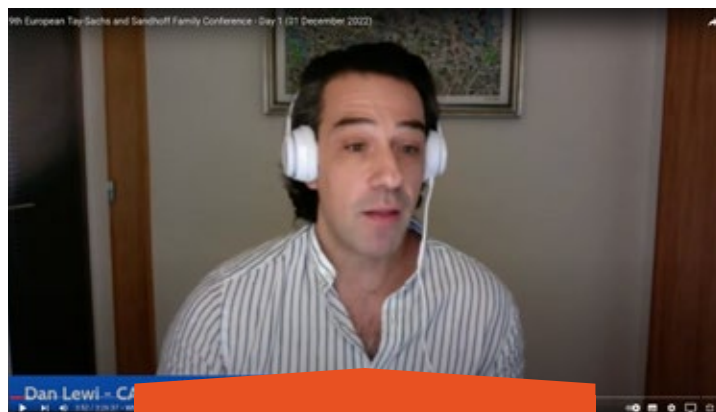
The first part of day one of the conference was focusing on clinical trial adherence and why this is so important. Speakers from Niemann-Pick UK, Sanofi and Congnitant discussed the topic in great detail to help us understand the potential negative impact that happens when someone drops out of a study. The panel, joined by the advocacy groups gave additional insights on this topic which we hope has given our community a greater understanding of why it is just an important item to be discussed.

The second part of the first day had speakers who gave an overview of how information can be accessed online. Speakers from RARE Revolution, EURORDIS and the advocacy groups discussed the topic in greater details which enabled us to hear about how information has developed over the last 25 years. Our final panel gave us the opportunity to hear about more exciting projects that have been launched in the rare diseases space and also for our community. You can watch the presentations on YouTube via the button on each summary page.

Gaining a deeper understanding of some important topics

"I knew that clinical trial adherence was important, but I didn't really understand the implications of someone dropping out of a study. To hear the view of advocacy, patients and industry on the same topic was great."

Conference attendee



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PRESENTATION 1

13:05 - 13:15

Who is the ETSCC and why was the consortium established?

Dan Lewi gave an overview of why the ETSCC was established and what we are working together as a group. The talk gave a brief history of the consortium, the journey that we have been on since 2013 and how we are planning on working together in the future.



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DAN LEWI

Chairman of the ETSCC & Co-founder of the Cure & Action for Tay-Sachs (CATS) Foundation

To watch the [presentation click here](#)

PRESENTATION 2

13:15 - 13:30

The ACTAYS family psychological programme for clinical trials

Beatriz Fernández Domínguez gave an overview of the project that ACTAYS have started that is focusing on preparing Tay-Sachs and Sandhoff families for learning about clinical trials. The presentation discussed the psychological assistance that they provide to families.



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BEATRIZ FERNÁNDEZ DOMÍNGUEZ

Fundadora y Directora General at ACTAYS

To watch the [presentation click here](#)

PRESENTATION 3

13:30 - 13:45

What are the real life challenges to adherence to a clinical trial?

Toni Mathieson gave a presentation about the challenges that focused on how the Niemann-Pick patient community she represents have faced with their clinical trials over the years. The talk also touched on the work they have done to keep patients engaged in the studies.



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TONI MATHIESON

CEO of Niemann-Pick UK (NPUK)

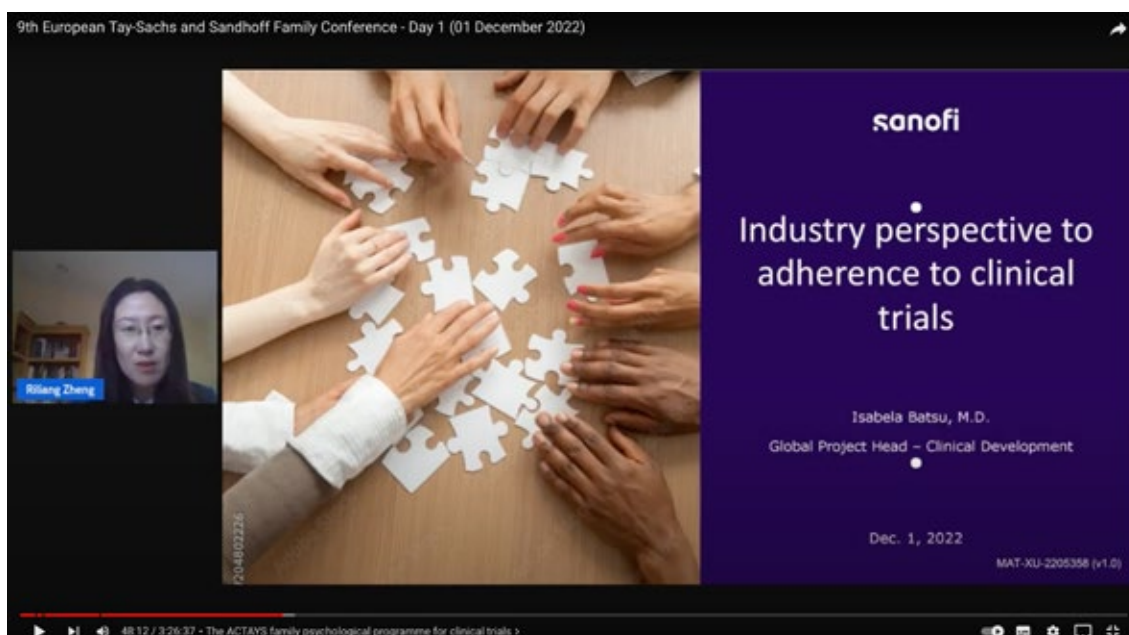
To watch the [presentation click here](#)

PRESENTATION 4


13:45 - 14:00

Industry perspective to adherence to clinical trial

Riliang Zheng gave a presentation that focused on the industry perspective to adherence to clinical trials. The talk focused on how Sanofi help to keep patients stay engaged in a clinical trial and what steps can be taken to address this really important topic.



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ISABELA BATSU & RILIANG ZHENG

Global Project Head, Clinical Development, Rare Diseases; and Clinical Research Director

To watch the [presentation click here](#)

PRESENTATION 5

14:00 - 14:15

How can education help people adhere to a clinical trial?

Alex Merckx gave a presentation on why technology is becoming more important in clinical trials in relation to trial adherence. Alex gave an overview of a project that Cognitant has worked on to address this topic by using digital educational materials to support patients.



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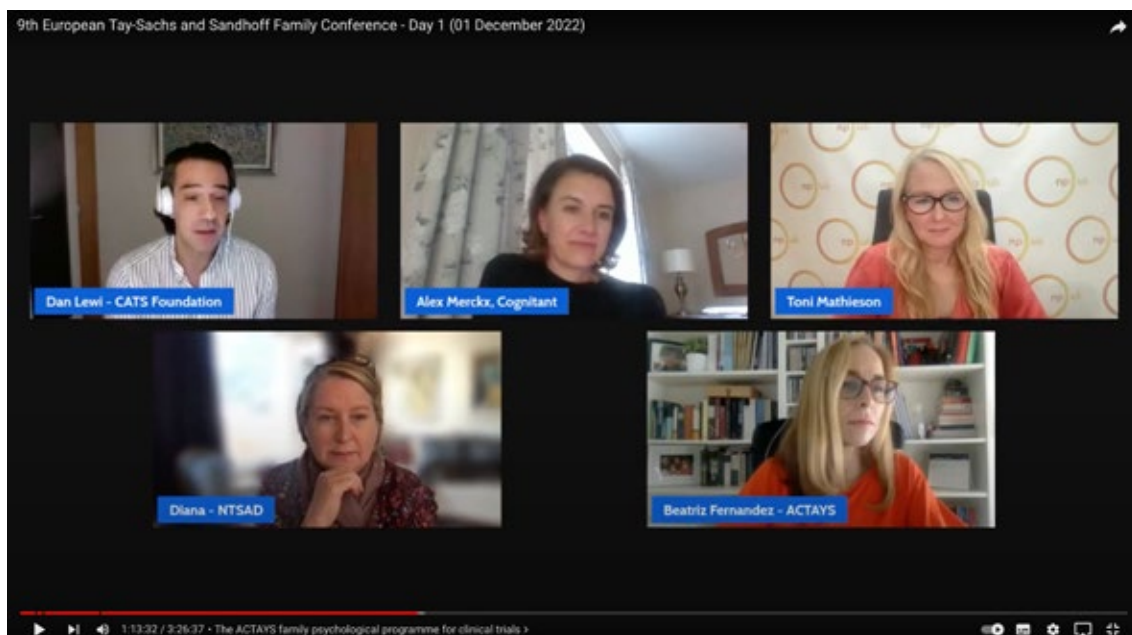
ALEX MERCKX
Director of Marketing and Partnerships at Cognitant
To watch the [presentation click here](#)

PANEL DISCUSSION

14:15 - 14:30

Why is adherence such a challenge and what can we do to make it easier for families?

The panel, with speakers from Cognitant, NPUK, NTSAD and CATS discussed the topic of clinical trial adherence. The role that advocacy can play in sharing information was also discussed and how steps can and should be taken to educate our families.



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PANEL ATTENDEES

Dan Lewi; Beatriz Fernández Domínguez; Toni Mathieson; Alex Merckx; and Diana Pangonis

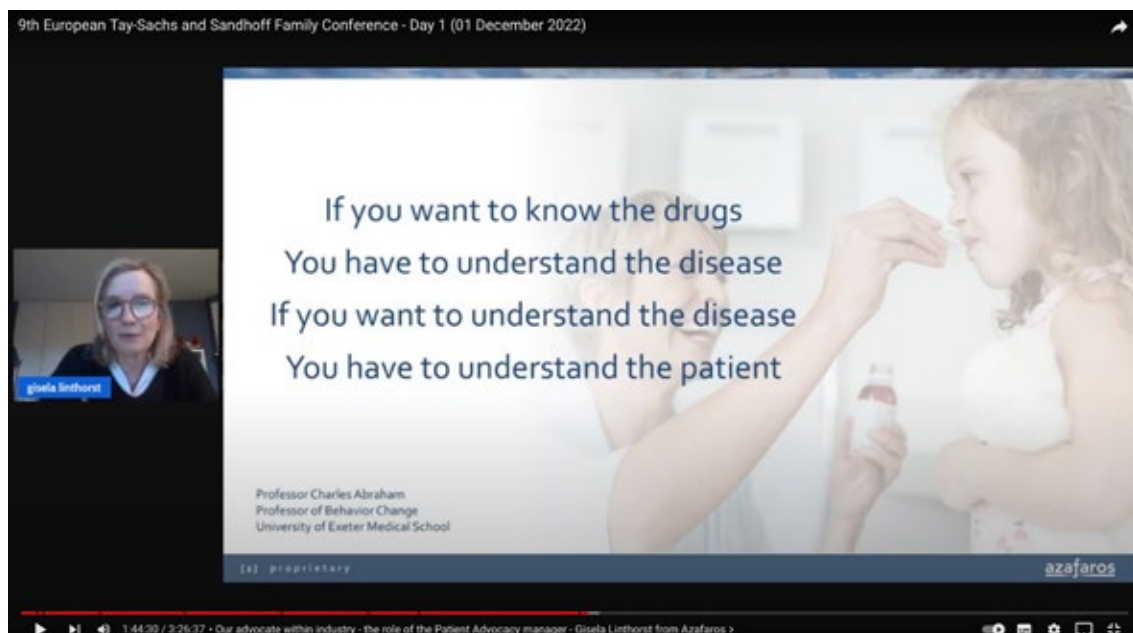
A row of logos for the panel attendees: COGNITANT (reimagining health information), npuk (National Tay-Sachs & Allied Diseases Association), ACTAYS (ACCION Y CLIMA PARA TAY-SACHES), CATS (CURE & ACTION FOR TAYSACHS FOUNDATION), and National Tay-Sachs & Allied Diseases Association (NTSAD).

PRESENTATION 6

14:40 - 14:55

Our advocate within industry - the role of the Patient Advocacy Manager

Gisela Linthorst gave a presentation which discussed her role as a Patient Advocacy Manager at an industry partner. The talk touched on how this role has developed over the years and how her colleagues work directly with lots of different advocacy groups.



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GISELA LINTHORST

Head of Patient advocacy and Patient Engagement at Azafaros

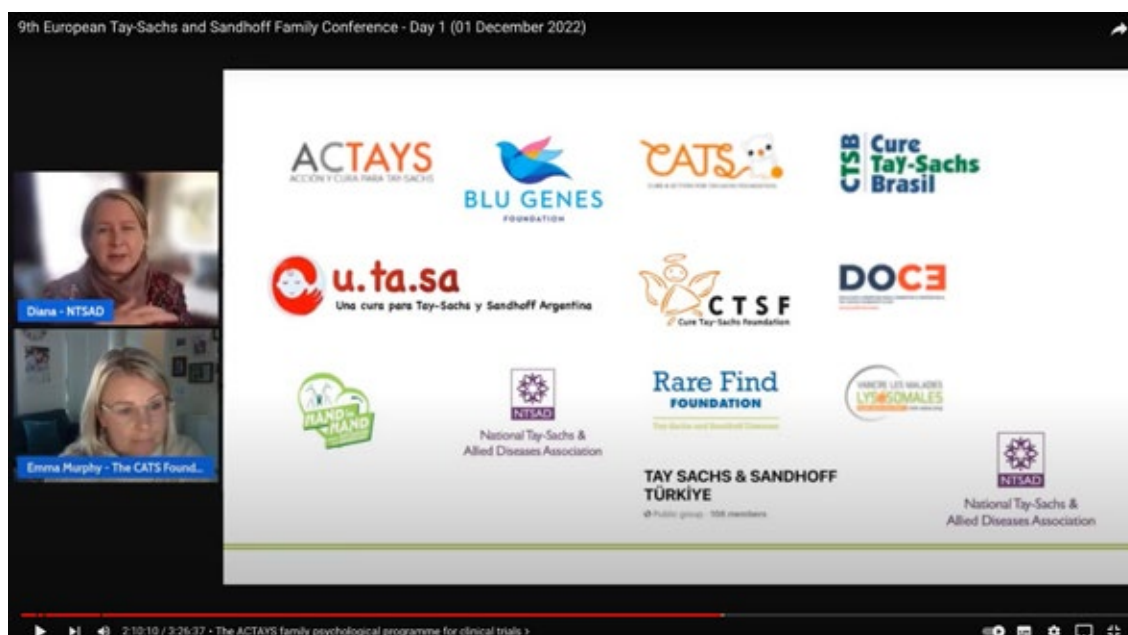
To watch the [presentation click here](#)

PRESENTATION 7



14:55 - 15:10

What and where? Navigating information online

Diana Pangonis with over 20+ years in advocacy was joined by Emma Murphy to discuss the ways in which advocacy groups are continually working on showing how and where families can access reliable information about Tay-Sachs and Sandhoff.



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DIANA PANGONIS & EMMA MURPHY &

Director of Family Services at NTSAD; and Family Support Officer at The CATS Foundation

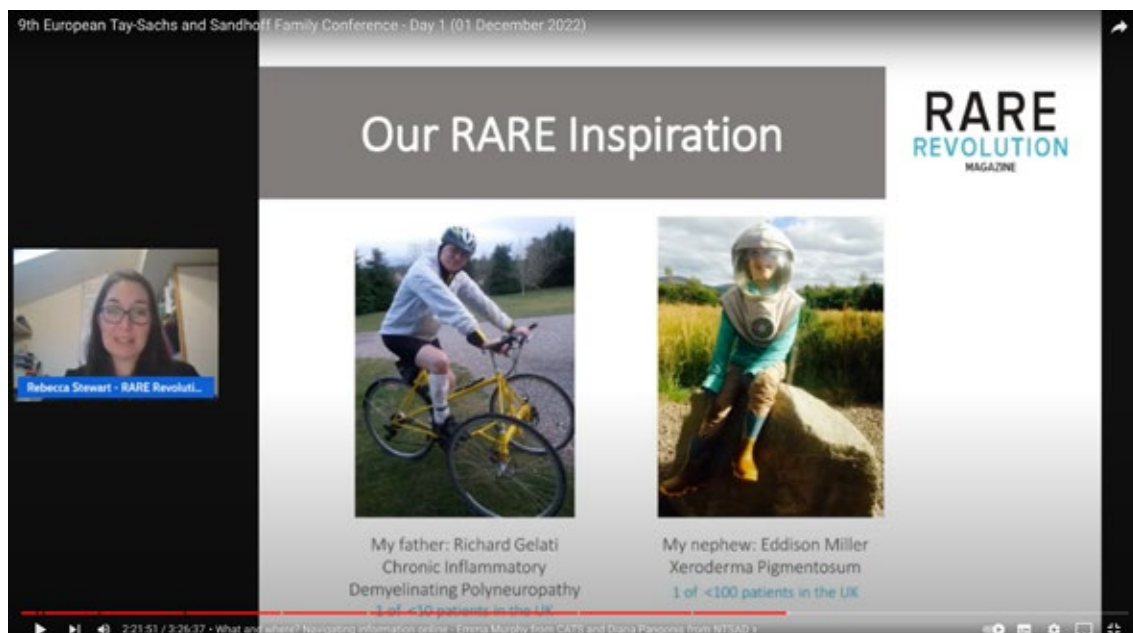
To watch the [presentation click here](#)

PRESENTATION 8

15:10 - 15:25

Hot off the press - your monthly RARE digital magazine

Rebecca Stewart gave a presentation that introduced our community to RARE Revolution magazine and the work they have been doing to raise awareness of rare diseases. With the publication they have been able to make a big impact on how patients and families can share their stories.



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REBECCA STEWART

Co-founder of Rare Revolution

To watch the [presentation click here](#)

PRESENTATION 9

15:25 - 15:40

Patient Engagement in regulatory activities

Maria Cavaller gave a presentation that focused on providing an overview of the patient engagement that the EMA undertakes with different communities. The talk highlighted the work they have been doing at making information accessible to patients and their families.



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MARIA CAVALLER

Patient Engagement at EURORDIS

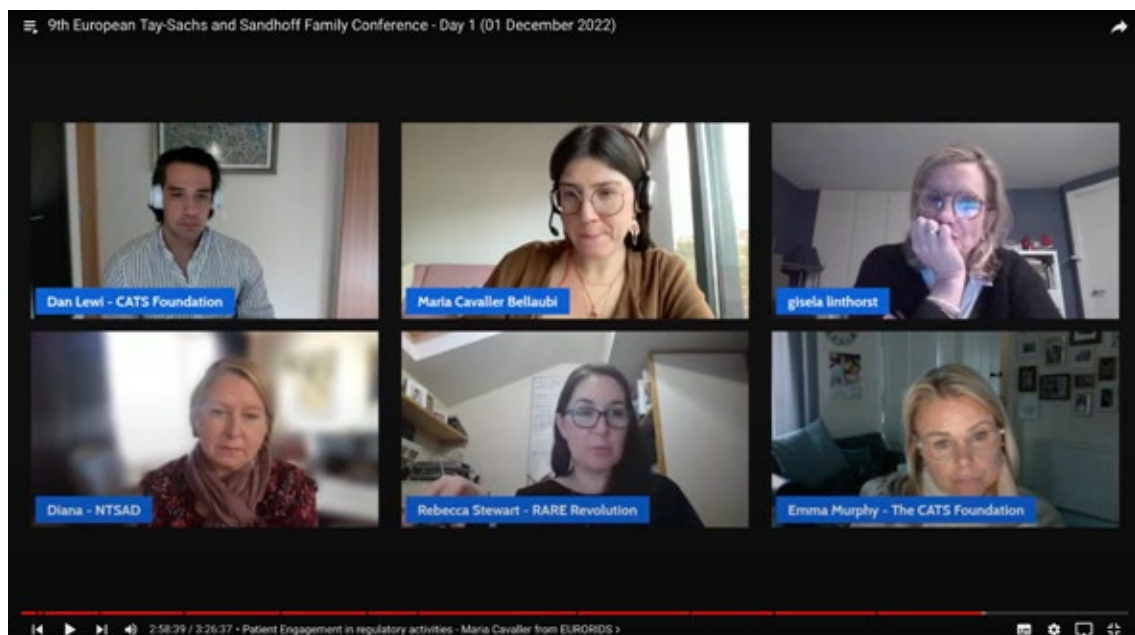
To watch the [presentation click here](#)

PANEL DISCUSSION

15:40 - 15:55

What are the challenges of finding the right information about Tay-Sachs and Sandhoff?

The final panel of the day, with speakers from Azafaros, CATS, EURORDIS, RARE Revolution and NTSAD discussed the topic of access to information for our community. The topics included the challenges our families face and how these can be overcome.



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PANEL ATTENDEES

Dan Lewi; Emma Murphy; Gisela Linthorst; Rebecca Stewart; Maria Cavaller; and Diana Pangonis







SUMMARY

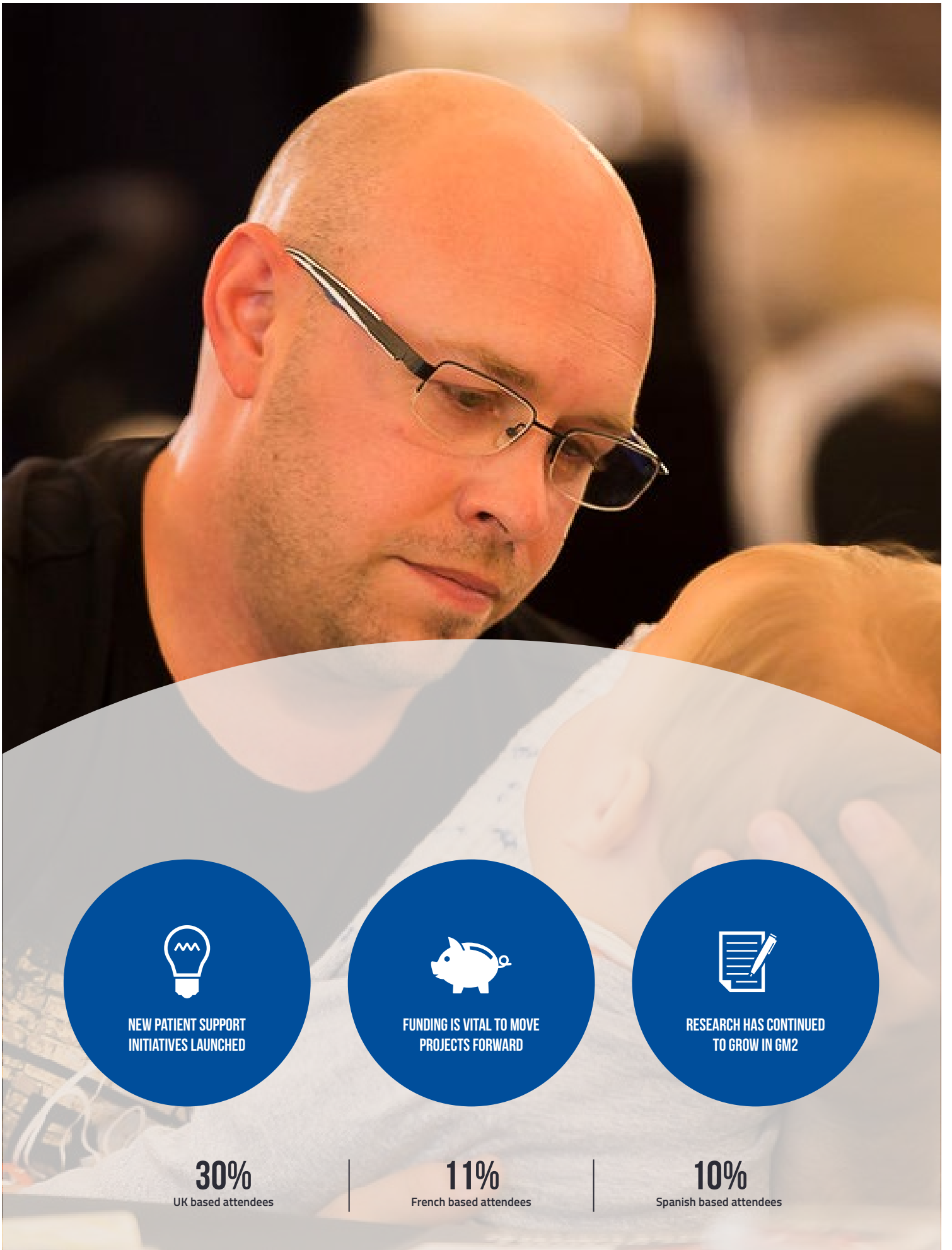
DAY 1

A day that focused on educating and empower our Tay-Sachs and Sandhoff community

Each of the presentations have a unique insight to the topics of clinical trial adherence and access to information for our community. To hear about the lessons learnt from other advocacy groups will help us all prepare how we can keep our families engaged in clinical trials as they start to move forward. Learning about the role of an Advocacy Manager has helped our families understand about how they work closely with all the advocacy groups. The panel discussions were very interesting and raised many points we need to consider in these topics.



[CLICK HERE TO WATCH THE SUMMARY](#)



**NEW PATIENT SUPPORT
INITIATIVES LAUNCHED**

30%
UK based attendees



**FUNDING IS VITAL TO MOVE
PROJECTS FORWARD**

11%
French based attendees



**RESEARCH HAS CONTINUED
TO GROW IN GM2**

10%
Spanish based attendees

DAY 2

INTRODUCTION

Keeping our community up to date on the latest research being conducting in Tay-Sachs and Sandhoff is vital as it enables all our families to see the progress that is being made as we work towards treatment options

In 2022 we saw many ups and downs in the research for treatments into Tay-Sachs and Sandhoff. At the beginning of the year it was looking very promising with the range of companies looking into utilizing different therapeutic techniques to provide both symptomatic and potential curative results. Sadly, we some of the companies investigating these treatments withdrew from our space which has left a void that we are hoping will be filled by other industry partners.

However, the companies that joined us to present on second day of the conference all had very interesting and exciting updates to share.. They are all fully committed to continue developing these treatments as we all work towards having an option for our community. In addition to these companies, we were joined by Professor Cox who was able to provide a brief history of the diseases and how the various treatment options have been developed. You can watch the presentations on YouTube via the button on each summary page.

Research into Tay-Sachs and Sandhoff continues to progress

“Every year it’s really interesting to hear the progress that has been made in the research for treatments. It’s never going to be quick enough, but it is encouraging to see that the companies are driving forward all the time.”

Conference attendee



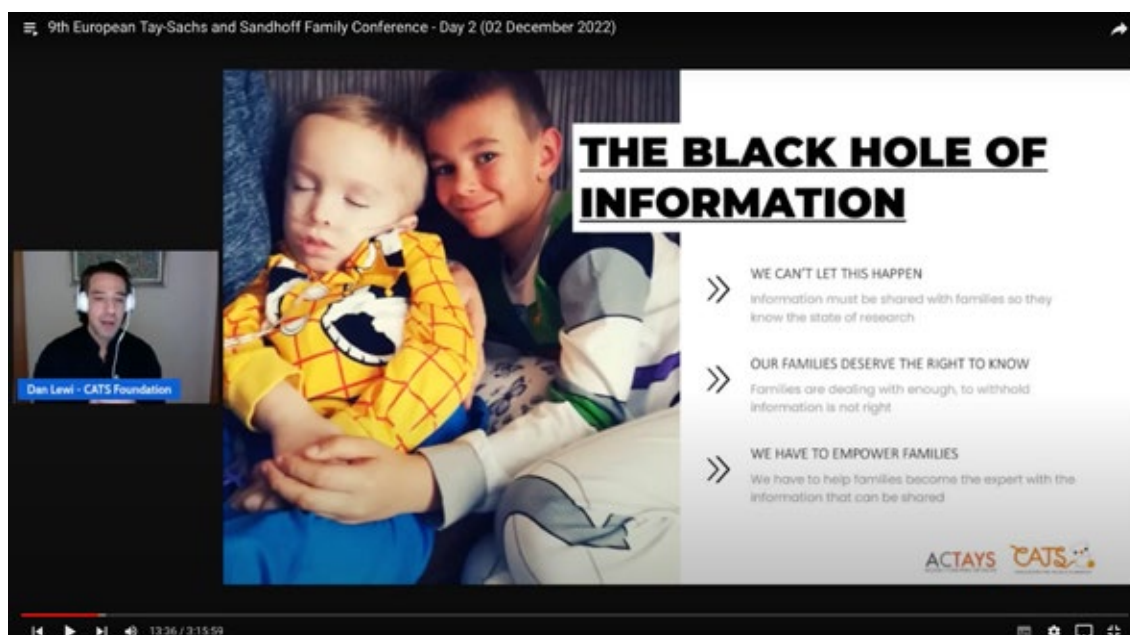
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PRESENTATION 10

13:10 - 13:25

Our community and it's involvement in research thre research for Tay-Sachs and Sandhoff

Dan Lewi gave a presentation about the Tay-Sachs and Sandhoff community involvement in research. The talk touched on our importance in developing treatments and how all the advocacy groups have been working hard for many years to make these treatments a reality.



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DAN LEWI
Chairman of the ETSCC & Co-founder of the Cure & Action for Tay-Sachs (CATS) Foundation
To watch the [presentation click here](#)

PRESENTATION 11

13:25 - 13:40

Introduction to JCR Pharmaceuticals

Mathias Schmidt gave a presentation which introduced JCR Pharmaceuticals to the Tay-Sachs and Sandhoff community in Europe. The talk gave an overview of the work they are planning on developing for our community.



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MATHIAS SCHMIDT

President & CEO of JCR USA, Inc.

To watch the [presentation click here](#)

PRESENTATION 12

13:40 - 13:55

Updates on the Development of IB1001 for GM2 Gangliosidoses

Taylor Fields provided an update on the IB1001 trial for Tay-Sachs and Sandhoff. The talk focused on the plans for the study in the next 12 months and how their work in Niemann-Pick C has also been progressing in the clinic.

9th European Tay-Sachs and Sandhoff Family Conference - Day 2 (02 December 2022)

IB1001-202 Trial Design

IB1001 master protocol designed to (i) account for the heterogeneity of NPC symptoms / intra-patient variability; (ii) be clinically relevant; (iii) capture clinically meaningful changes in functioning; (iv) minimize bias in the blinded primary assessment

Design

- Open-label, rater-blinded
- Parent Study:** Symptomatic Treatment: Baseline period: 6-week treatment period, post-treatment washout
- Extension Phase:** Neuroprotective, Disease Modifying Treatment

Dose

- Orally administered (batches)
- 13 years & older: daily dose of 4 g/day
- 6-12 years: weight based doses (2 – 4 g/day)

Key Eligibility Criteria

- Confirmed diagnosis of GM2
- 6 years + EU/ 18 years + USA
- SARA score of 5 – 33 and able to walk with aid or perform SHPT-D
- No prohibited medications used within 42 days of screening

PARENT STUDY

BASELINE (2 weeks) | TREATMENT (6 weeks) | WASHOUT (6 weeks)

EXTENSION PHASE (EP)

EP TREATMENT (12 weeks) | EP WASHOUT (6 weeks)

Visit 1 (Baseline 1) | Visit 2 (Baseline 2) | Visit 3 (Treatment 1) | Visit 4 (Treatment 2) | Visit 5 (Washout 1) | Visit 6/7 (EP Baseline) | Visit 8 (EP Treatment 1) | Visit 9 (EP Treatment 2) | Visit 10 (EP Washout)

Fields et al. 2022

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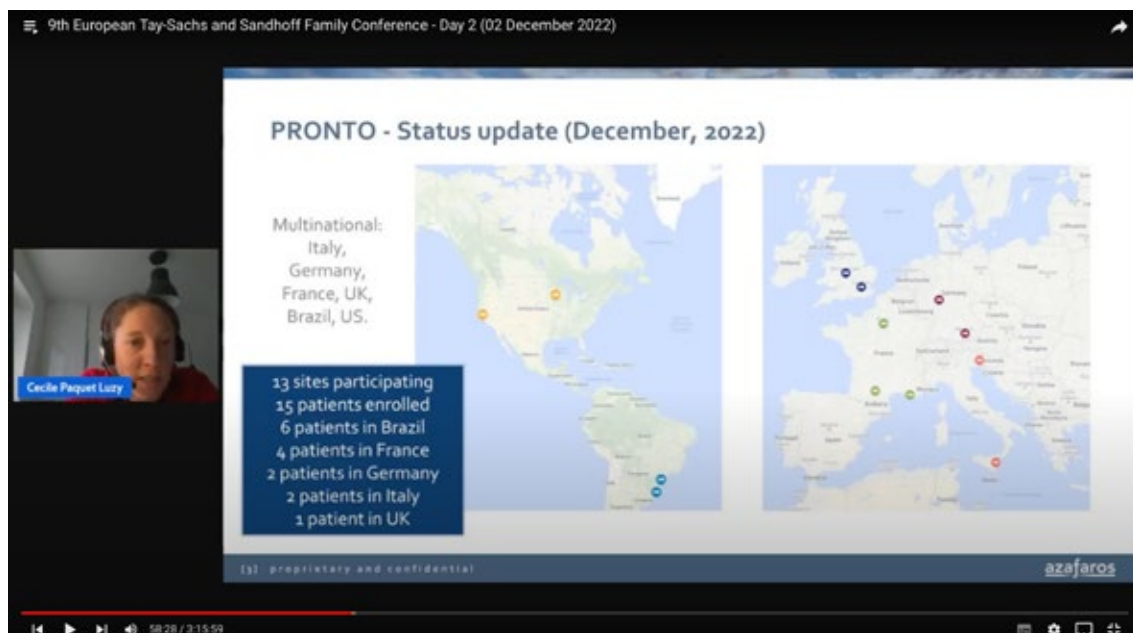
TAYLOR FIELDS
 Chief Product Development Officer at IntraBio
 To watch the [presentation click here](#)

PRESENTATION 13

13:55 - 14:10

Azafaros and its work in Tay-Sachs and Sandhoff

Cecile Paquet Luzy gave a presentation which provided an update on the PRONTO study that Azafaros are currently running. The talk also discussed the company's plans for the future in the Tay-Sachs and Sandhoff space and how we as patients and families can support them.



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CECILE PAQUET LUZY

Head of Clinical Science at Azafaros

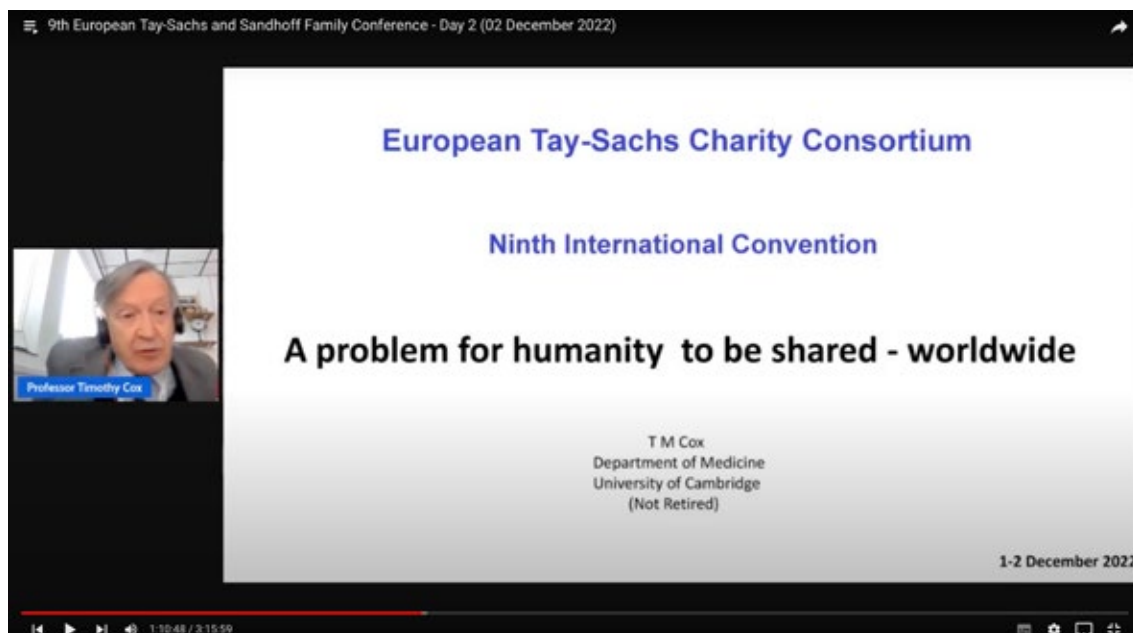
To watch the [presentation click her](#)

PRESENTATION 14

14:10 - 14:40

Overview of the research and treatments for Tay-Sachs and Sandhoff

Professor Timothy Cox gave a presentation which talked through the history of Tay-Sachs and Sandhoff. The talk was aimed at giving our attendees a deeper understanding of all the work that has been undertaken historically to identify potential treatment options.



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PROFESSOR TIMOTHY COX

Professor of Medicine (Emeritus) and Honorary Consultant Physician at The University of Cambridge

To watch the [presentation click here](#)

PRESENTATION 15

14:50 - 15:05

Clinical development journey of Venglustat (GCS inhibitor) in GM2 Gangliosidosis

Riliang Zheng gave an update on the clinical development journey of Venglustat (GCS inhibitor) in GM2 Gangliosidosis. The talk focused on Sanofi's experience in rare disease and how the treatment has gone through the various development phases.

9th European Tay-Sachs and Sandhoff Family Conference - Day 2 (02 December 2022)

Venglustat reduces GL-1 (and related glycosphingolipids) and increases survival in nonclinical studies

- CNS exposure and GL-1 lowering demonstrated with GZ402671 in normal rodents
- Increased survival and CNS GL-1 and lyso-GL-1 lowering with GZ402671 in 4L^{C+} mice (neuronopathic GD model)
- Increased survival and CNS GM2/lyso-GM2 lowering with GZ402671 in *hexb*^{-/-} Sandhoff mice

Increased survival of Sandhoff mice treated with GZ402671

GL-1 and lyso-GL-1 reductions in nGD mice treated with GZ402671

Reduction of GM2 and lyso-GM2 in brain of Sandhoff mice treated with GZ402671

Legend: WT, SRT, SD, SRT, SRT

Legend: WT, SRT, SRT, SRT

Legend: WT, SRT, SRT, SRT

sanofi

UNT: untreated; SRT: Treated with substrate reduction therapy; WT: wild type (no disease); SD: mouse with Sandhoff Disease

Substrate Reduction Therapy for Sandhoff Disease through Inhibition of Glucosylceramide Synthase Activity Molecular Therapy Vol. 27 No 8 August 2023, The American Society of Gene and Cell Therapy.

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ISABELA BATSU & RILIANG ZHENG

Global Project Head, Clinical Development, Rare Diseases at Sanofi ; and Clinical Research Director at Sanofi

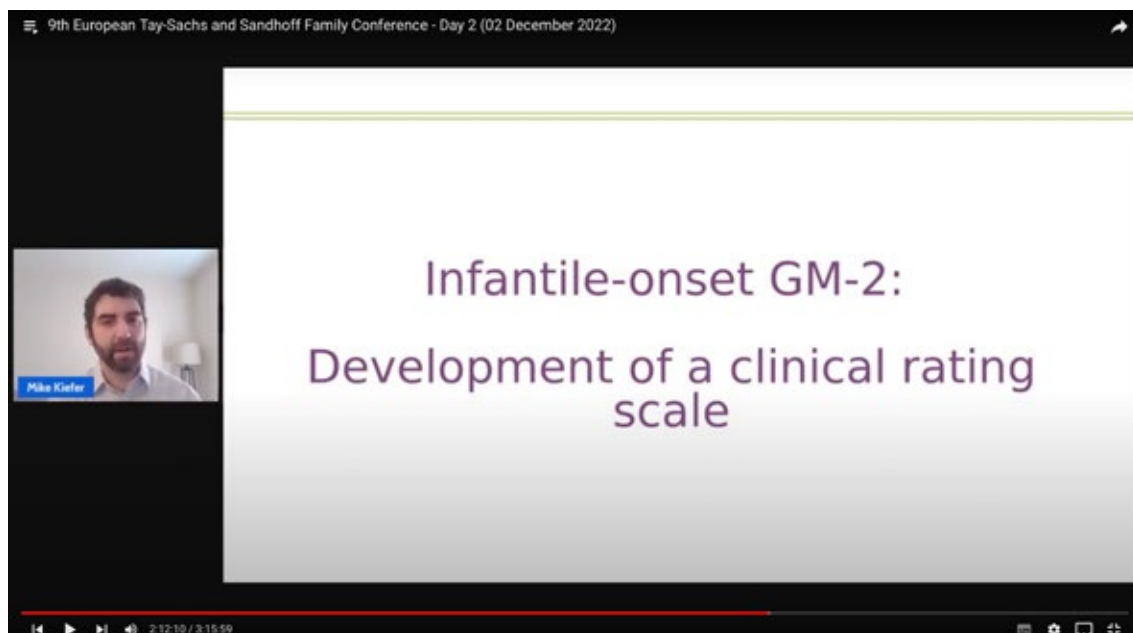
To watch the [presentation click here](#)

PRESENTATION 16

14:10 - 14:40

Construction and validation of the Infantile onset GM2 Gangliosidosis rating scale

Michael Kiefer gave a presentation on a study being conducted to develop a virtual clinical assessment tool for Infantile onset GM2. The talk focused on how this scale will be developed so that a disease specific tool can be used to assess potential treatments.



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MICHAEL KIEFER

Doctoral Research Fellow at MGH Institute of Health Professions

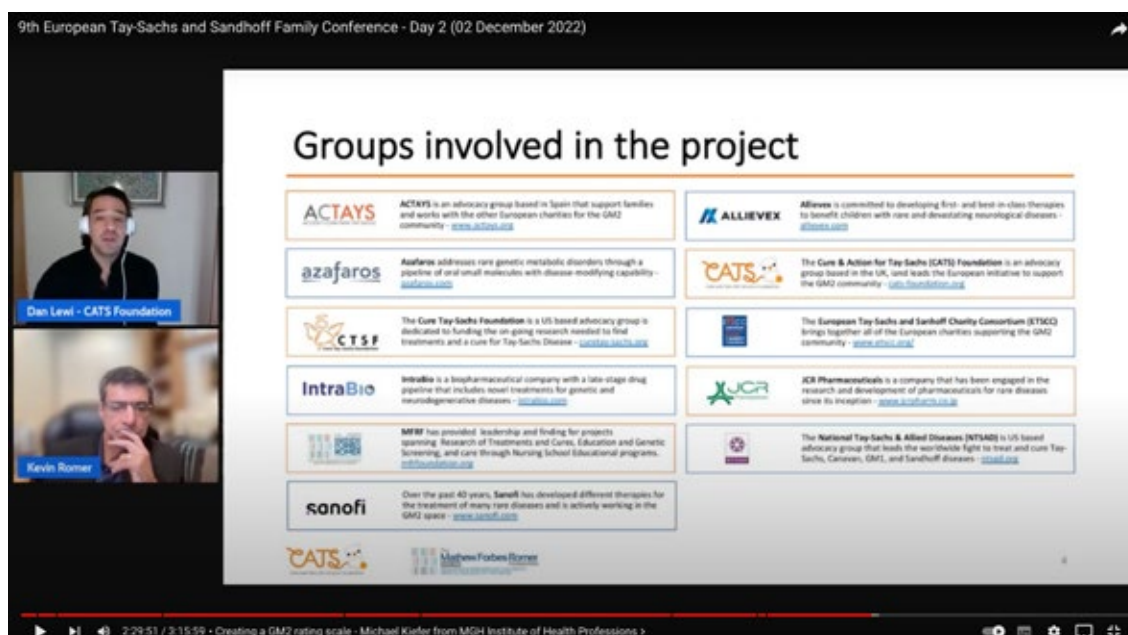
To watch the [presentation click here](#)

PRESENTATION 17



15:20 - 15:35

Establishing a global working community for Tay-Sachs and Sandhoff

Dan Lewi and Kevin Romer presented the vision for a global initiative that brings together expertise from all the Tay-Sachs and Sandhoff advocacy groups and companies. The talk discussed the plans of how this group will be brought together and the projects it will tackle.



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DAN LEWI & KEVIN ROMER

Chairman of the ETSCC & Co-founder of the CATS Foundation; and President & Co-Founder Mathew Forbes Romer Foundation

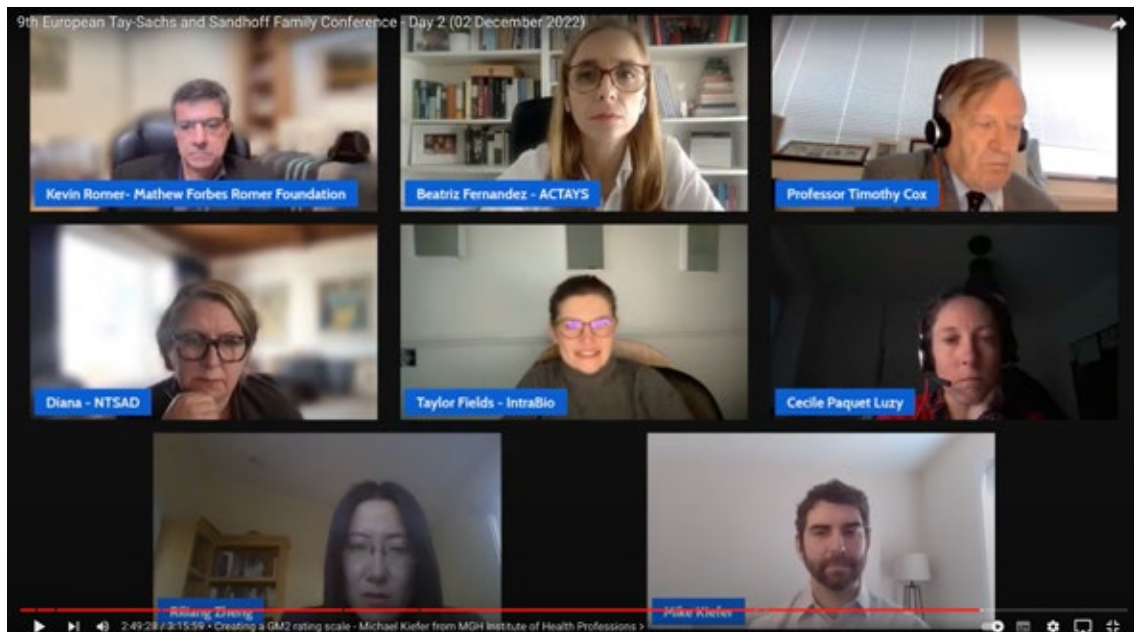
To watch the [presentation click here](#)

PANEL DISCUSSION

15:35 - 15:50

What does the future hold for the GM2 community?

The final panel of the conference was attended by representatives from the day's speakers. The topics discussed focused on the future of treatments for Tay-Sachs and Sandhoff and how we can all help drive them forward for the community.



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PANEL ATTENDEES

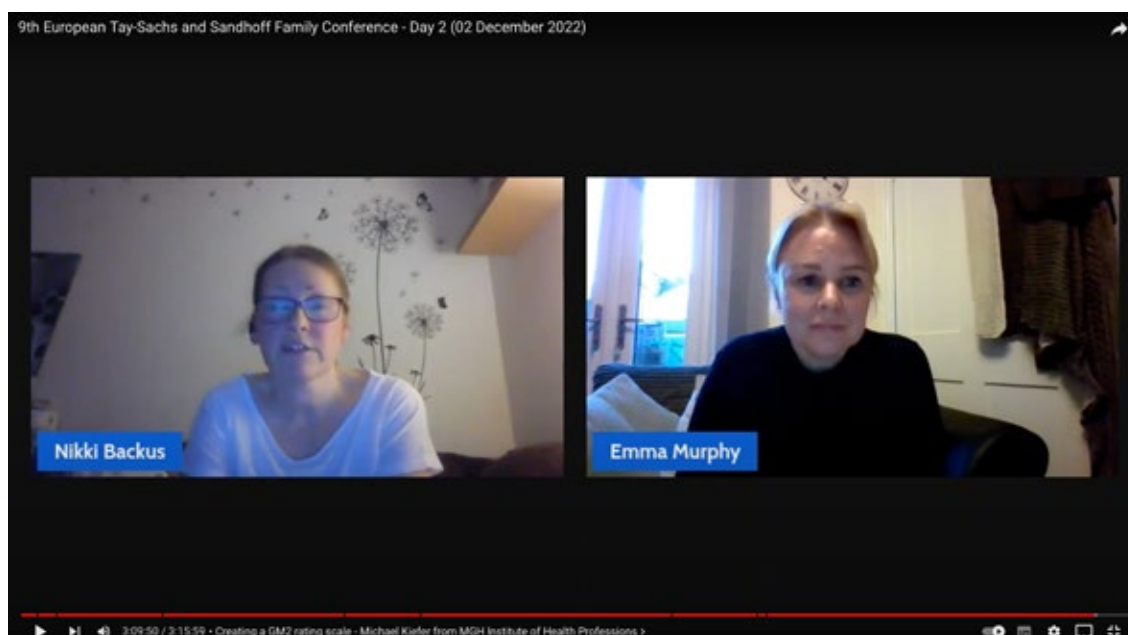
Beatriz Fernández Domínguez; Professor Timothy Cox; Taylor Fields; Kevin Romer; Cecile Paquet Luzy; Riliang Zheng; Michael Kiefer; and Diana Pagonis

PRESENTATION 18

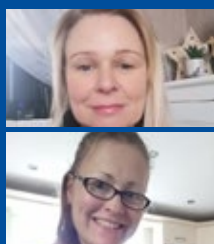
15:50 - 15:55

Working with the siblings in the Tay-Sachs and Sanhoff community

Nikki and Emma gave a presentation on the work that The CATS Foundation has been doing with siblings to ensure they are getting all the support that they need. The talk introduced the many projects that the team started in 2022 and will continue through 2023.



[CLICK HERE TO WATCH](#)



EMMA MURPHY & NIKKI BACKUS

Family Support Officers at The CATS Foundation

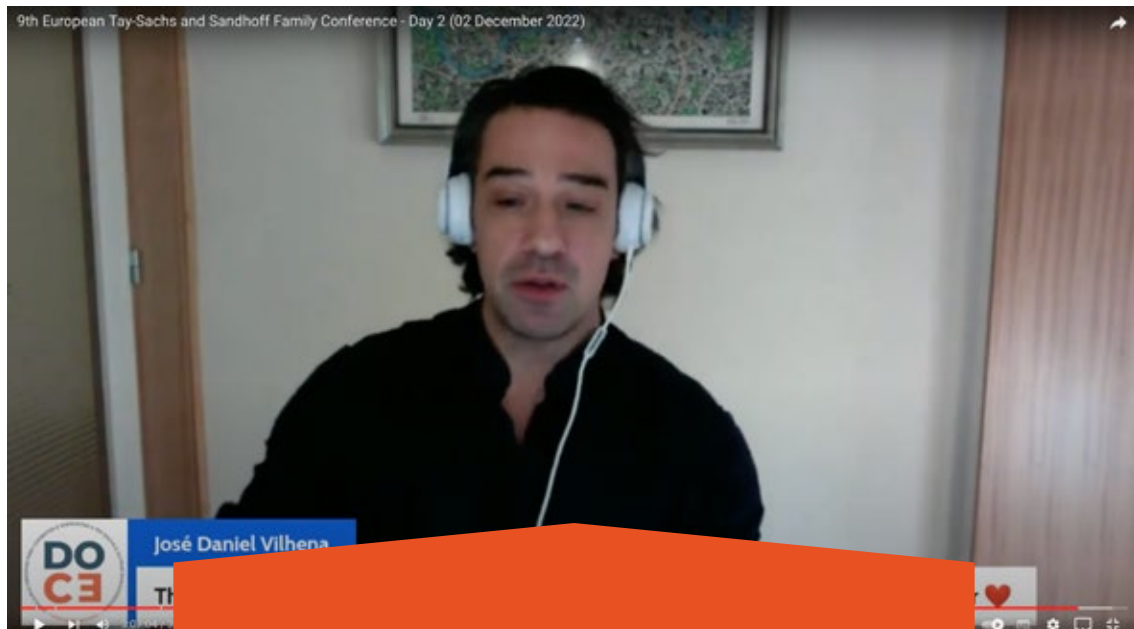
To watch the [presentation click here](#)

SUMMARY

DAY 2

A day of updates on the future of treatments for Tay-Sachs and Sandhoff

In 2022 we saw some of the treatments being investigated for Tay-Sachs and Sandhoff move forward, and sadly we saw some studies stopped. The impact that can have on our community is huge as we continue to drive forward treatment options for the diseases. It was encouraging to hear the developments from some of our industry partners and we are looking forward to seeing how they continue to drive forward in 2023. The final panel gave an interesting viewpoint from our speakers about the future for Tay-Sachs and Sandhoff.



[CLICK HERE TO WATCH THE SUMMARY](#)

ETSCC GOALS FOR 2023

1

WORK TOGETHER ON THE DEVELOPMENT OF TREATMENTS FOR OUR COMMUNITY

As a consortium, all member of the ETSCC will continue to work collaboratively for the Tay-Sachs and Sandhoff community so that we help bring treatments to families.

2

ADVOCATE FOR FAMILIES SO THEY HAVE ACCESS TO ALL THE SUPPORT THEY NEED

Each consortium member will continue to share and advise each other so that we can ensure that families have access to all support they need to manage.

3

JOIN THE GLOBAL INITIATIVE TO WORK TOGETHER FOR OUR COMMUNITY

The consortium members plan to join the global initiative so that we can enhance our collective power in leading projects for the Tay-Sachs and Sandhoff community.

4

PLAN BOTH AN IN-PERSON AND VIRTUAL CONFERENCE IN EUROPE FOR 2023

For 2023 we plan to hold an in-person event in Europe for the first time since 2019 to bring together our families and we will supplement this with a virtual event.





A present for my sister

Join Rose as she goes on a journey to find the perfect present for her special sister Sadie. Although Sadie isn't very well, there is one gift that Rose, and her little brother Tom can give her that will mean more than anything in this world. What do you think it is?



www.cats-foundation.org



A present for my sister



The (CATS) Foundation



[in linkedin.com/company/etscc](https://www.linkedin.com/company/etscc)
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