



Curriculum Vitae

Personal information **Patricia Felgueiras Seabra Duro**

Work experience

June 2011 – Present Cure & Action for Tay-Sachs (CATS) Foundation

Co-founder and Executive Director

In 2011 my husband and I founded the charity Cure & Action for Tay-Sachs (CATS) Foundation after our daughter

was diagnosed with the rare and terminal genetic disease called Tay-Sachs. At the time there was no European

charity providing support and information about the disease to families. Under my leadership I have been able to

develop a successful charity which has a visual brand along with very clear objectives. We are recognised as the

leading Tay-Sachs charity in Europe. I have developed close links with our US counterparts along with assisting

European and Australian based charities to become established which run alongside the charity model I implemented.

On a personal level I have become an accepted expert in the paediatric rare disease community and have featured in numerous publications giving my view on Tay-Sachs and the challenges families face. I lead the peer-to-

peer support model we implemented so that families always have someone they can turn to for advice. Our

own experience of feeling isolated after diagnosis no longer happens after our work both with national health

services and on an international level to provide the right information to families at the right time.

I am currently a patient advocate member of the International Rare Diseases Research Consortium (IRDIRC)

“New Technology Task Force”, which has the objective to identify new technologies in development or in experimental use which are likely to increase the diagnostic rate for patients and to identify opportunities to enable

the safe, widespread clinical adoption of the most effective technologies in a meaningful timeline. Working with a

very diverse group of scientists, researchers, and patient advocates from around the world in bringing forward

change for patients.

March 2012 – Present European Tay-Sachs Charity Consortium (ETSCC)

Advocacy representative

In 2012 the European Tay-Sachs Charity Consortium (ETSCC) was launched to bring together all the European

Tay-Sachs charities to provide a unified voice for the diseases. As a representative of the consortium my responsibilities include:

- Liaise with European health care professionals regarding the best practices of caring for children affected by

Tay-Sachs and Sandhoff disease;

- Organise annual family conferences with attendees from all over Europe (both in person and virtual);

- Aid in the set-up of new European charities alongside our proven and successful charity model;

- Worked with international researchers, in an advisory role and on behalf of the patient and health professionals' community, on the design and development of therapies and clinical trials for Tay-Sachs and

Sandhoff.

March 2011 – December 2017 Full-time carer

Full-time carer

After my eldest daughter was diagnosed with Tay-Sachs disease I was her full-time carer alongside my other

commitments. This involved managing her condition as the disease progressed and ensuring that she was able to

have the highest quality of life as possible where she eventually required 24-hour care.

During this time, I set up The CATS Foundation with my husband where I established the organisation, managed

its growth and set clear objectives as we drove forward treatments for the disease. I was also involved in the

establishment of the ETSCC and helped set-up sister charities throughout Europe so that there was widespread

support for families affected by Tay-Sachs and Sandhoff disease. The key to being able to manage this alongside

my carer responsibilities was being able to multitask and leverage the expertise of those people around

me, our daughter and the charity. During this time, I also had my third child.

October 2014 – October 2015 Consultancy

Freelance Consultant

As my daughter's condition continued to deteriorate, I took the decision to become a freelance consultant in the field of children's wear. In this role I consulted for various high-end brands on their production and buying and used both my contacts and particularly my negotiating skills in setting up strong relationships between brands and factories and brands and clients.

July 2012 – October 2014 AlexandAlexa

Production Manager

As the senior Production Manager, I was responsible for the technical management, supervision and control of the production processes for the entire AlexandAlexa label which was newly launched. This role involved dealing with designers from product concept, procuring and negotiating with international factories, analysing prices, quantities and build sales forecasts and manage the entire production timeline, ensuring that every single component of the garment production falls in-line for successful and timely delivery. I was part of the team which set up the new brand for the company and led not only the production, but also its launch. The brand was an award-winning range and its success kickstarted AlexandAlexa's entry to their own children's wear label. During this time, I had my second child.

July 2010 – July 2012 Marie Chantal

Wholesale Manager

As the Wholesale Manager I was responsible for the management of the production and sale of the Marie Chantal collection to our wholesale clients. Having a small presence in the UK and US when I first joined, the aim of my role was to expand the brand to several European countries and Australia. This role involved regular meetings and managing the process of how the brand was positioned to international clients, exhibiting at trade shows in Paris, London, Florence and New York and that the production met client orders. This was a fast-paced role, that demanded highly analytical and social skills, extensive international travel and business acumen.

March 2009 – July 2010 Consultancy

Freelance Consultant

As a freelance consultant I consulted for various high-end children's wear European brands. I implemented various strategies and processes for the wholesale and production functions to improve efficiencies, reduce costs and raise profits. This was a highly analytical and negotiation-based role, where I used my experience both from my previous role and my education to steer brands in the right direction of sustainable growth. During this time my first daughter was born.

June 2002 – March 2009 Caramel Baby & Child

Wholesale & Production Manager

This dual role at a growing high end children's wear brand gave me valuable experience of working in a small but dynamic team. I led the wholesale and production operations as the company scaled, increasing in size through its online and physical shop presence. Working closely with the founder, I was involved in strategic decisions on the direction the company was moving towards whilst ensuring that the brand visibility increased. During my time we grew our wholesale operations by over 125% and opened three new shops.

Education and training

Qualifications

2021-online EURORDIS- Rare Diseases Europe

Leadership School on Healthcare and Research

The goal of the Leadership School is to give patient advocates the necessary tools and confidence to lead and advocate for their respective community. I found this course particularly helpful as it delved into subjects such as relationship management within the organisations, emotional balance, time management and how to present with impact. All tools that are vital in the patient advocacy field.

2021-online EURORDIS- Rare Diseases Europe

Open Academy School on Scientific Innovation & Translational Research

Aimed at deepening patient representatives' understanding on pre-clinical research and how it translates into real benefits for rare disease patients, I was fortunate to learn and hear from expert speakers and researchers from across Europe. The training provided targets themes of extreme unmet need in the paediatric sphere, such as history of genetics, diagnosis, new technologies in gene therapy and drug repurposing. Having been involved in

pre-clinical research projects myself, it felt reassuring to understand more on the subject and to be able to deepen

my own understanding and also to share my own experience with an international cohort of peer patient advocates who have very similar stories and goals as my own.

2020-online EURORDIS- Rare Diseases Europe

Digital School on Social and Digital Media

Since founding the CATS Foundation, the power of digital has been vital to reach communities, especially those

who are from European countries where there are no national Patient Organizations, where language often poses

a stumbling block in accessing information and connecting with the relevant healthcare professionals and clinicians. We have always had an outward view at CATS Foundation, first because the diseases affect beyond

borders, secondly because as an ultra-rare disease mostly affecting children and young people, success on

developing safe, efficacious and quality medicines is highly dependent on patient numbers. Connecting across

borders has always been vital for the Tay-Sachs and Sandhoff community, linking patients for peer-to-peer support, clinicians to share information on treatment options and researchers with patients so that the knowledge

transfer of disease practicalities and research progress is facilitated.

I joined the Digital School with a view to deepen my knowledge and acquire new techniques that would allow me

to improve our strategic outreach and community-building capacities. It was really enlightening to see a lot of what

I had implemented that had been right for our community and where improvements could be made.

Applying this

knowledge had direct impact in our work, particularly in patient engagement with the research work.

2020-online EURORDIS- Rare Diseases Europe

Open Academy School on Medicines Research and Development

Through this school which aims to provide patient advocates with the skills and knowledge needed to become

experts in medicines research and development, I was able to gain a more in-depth knowledge in a field which I

had been working in as a patient representative but purely with an empiric approach of my own life experience.

Covering topics like clinical trials methodology, clinical research, ethics in medicine development, the European

Regulatory Framework, health technology assessment and marketing authorisation – this course gave me extra

confidence in my abilities to further advocate for safe, efficacious and high quality medicines that are so desperately needed for our patient cohort, particularly the paediatric patients, which have more severe forms of

the diseases and who have a more limited access to medicines for the treatment of symptoms.

2020-online Innovative Medicines Initiative Conect4Children (IMI c4c)

Patient and Public Involvement in Paediatric Clinical Research

The Collaborative Network for European Clinical Trials for Children delivered this workshop which was incredibly

informative and enlightening. This course was of particular importance in giving me a more in-depth understanding of the European Paediatric Regulation and also an issue that affects the entire European paediatric

community – the high use of off label medicines, the challenges of conducting clinical trials in children and therefore the need for paediatric medicines that are of high quality, efficacious and safe is not only huge it is also

incredibly urgent. Having completed this course, I felt empowered to share with my own team and fellow patient

advocates the barriers but also the opportunities that us, as patient advocates face when advocating for the

medicines that our disease community, our children and indeed the entire paediatric patient community are entitled but often do not have access to. By sharing my findings and learnings I was able to expose the need for

us as advocates and our children and young people (CYP) cohort to be part of the process from the very beginning, how the CYPs have the right to participate in decisions that affect them and their health, how it should

be a democratic process and how it will improve research and study participation.

This course also empowered me to have more honest and direct conversations with some researchers, by making

the case for public patient involvement (PPI) partnerships, where mutual benefit is an obvious consequence for all

of the parties involved.

2020 Media Trust

Digital Summer School

Education

September 2003 – King's College London

July 2004 MBA

September 2001 – King's College London

July 2003 BSc (Hons) in Business and Managerial Economics

September 1999 – Faculdade de Economia do Porto _ Universidade do Porto

July 2001 BSc (Hons) in Business and Managerial Economics

September 1996 – Escola Secundária Aurélia de Sousa

July 1999 Diploma de Ensino Secundário, Ciências Socioeconómicas

September 1987 – Colégio de Nossa Senhora da Paz

July 1996 Primeiro e Segundo Ciclo

Languages

Portuguese 5 – Native

English 5 – Bilingual Proficiency

French 3 – Professional Working Proficiency

Spanish 3 – Professional Working Proficiency

Italian 2 – Limited Working Proficiency

Additional information

Publications

Projects

Memberships

Other Relevant Information I am a patient representative