

## ANNUAL REPORT FROM THE BOARD (2022)

### INTRODUCTION

In 2005, delegates from eight European countries met in Brussels to discuss the formation of a European umbrella of national and regional organisations of people affected by ADHD. The organisation was officially registered in Belgium in 2009.

ADHD Europe represents 21 European countries comprising of 31 organisational members, 16 professionals & 13 individuals from 25 European countries. Our membership also includes members from United States of America and international organisations are most welcome to join our community within ADHD Europe!

Our aim is to advocate for the rights of people affected by ADHD and comorbid conditions towards fostering inclusion and social justice on every level in Europe by being the ADHD voice. We actively contribute to research as the patient voice exchanging real-life experiences as well as meta-analytic reviews to better understand ADHD and its treatment. We support NGO's who assist people affected by ADHD who help them reach their full potential; experience well-being in their community and have access to diagnosis, treatment, supportive care, education, and employment. We promote evidence-based information by disseminating information at every European level to improve ADHD legislation. We are committed together in Europe spreading ADHD Awareness.

The Board, who are also the charity trustees, are responsible for the overall management and control of ADHD Europe.

### STRUCTURE, GOVERNANCE, AND MANAGEMENT

The Board, who are also the charity trustees, are responsible for the overall management.

Executive Board consists of the President, Treasurer, Secretary, and one Vice President who meet regularly and prepare the necessary prior to the Annual General Meeting.

The Board requires breadth and depth of experience to carry out its duties effectively and efficiently. All Board members give of their time freely and no remuneration was paid in the year.

### BOARD MEETINGS

The role of the Executive Committee is to manage and oversee all the legal and administrative work of ADHD Europe. It prepares paperwork and assists the President in preparing the Agenda for Board meetings. Especially the treasurer and secretary had a lot of work to manage the administrative tasks.

Although the Board is only required to meet four times in the year, the Board functions as an administrative body while there is no funding for any paid staff. This means the workload is spread across the Board.

In 2022 there were over 15 board meetings held online. Some of the meetings were just the Executive Committee, but most were with the full Board. Board members are very committed to their roles and have all put in many hours of their time over and above what is expected of them.

Fortunately, we managed to meet in person at the AGM in April in Cyprus and in October 14th to 16th in Leiden, Netherlands.

## **THE BOARD IN 2022**

### **President**

Dr. Myriam Bea (Elected June 2020 / end of term AGM 2023)

### **Vice President/s**

Andrea Bilbow (Elected June 2020 / until March 2022)

Hans van de Velde (Elected April 2021/ until November 2022)

### **Secretary**

Christina Georgiadou (Re-elected June 2020 /end of term 2023)

### **Treasurer**

Chantel Fouche (Re-elected April 2021 / end of term AGM 2024)

### **Ordinary Board Members**

Nina Hoven (Elected April 2021 / end of term AGM 2024)

Carola Stivala (Re-Elected April 2021 / end of term AGM 2024)

Hrannar Björn Arnarsson (Elected June 2020/ end of term AGM 2023)

Viljo Vilding (Elected April 2021 / until May 2022)

You can find out more about our board members at <https://adhdeurope.eu/meet-the-board/>

## **PROFESSIONAL ADVISORY BOARD**

Our professional advisory board exists to bring the perspective of professionals who work with ADHD to ADHD Europe and assist our Board where scientific knowledge is required.

### **The Professional Board in 2022**

Prof Sandra Kooij

Prof Philip Asherson Dr Dr Anthony Ramos

Prof Barbara Franke

Prof Tobias Banaschewski

Dr Kate Carr-Fanning

You can find out more about our professional advisory board members at <https://adhdeurope.eu/professional-advisory-board/>

## REVIEW OF ACTIVITIES AND ACHIEVEMENTS

The Board created subcommittees to look at different aspects of the organisation. We used the different strengths of our Board members to focus on different sections of our workplan.

### GOOD GOVERNANCE / STATUTES COMMITTEE

**Lead: Myriam Bea**

Supported by Viljo Wilding, Stephanie Clark, Joanne Norris, Chantel Fouche, Christina Georgiadou and other members

With regards to statutes, ADHD Europe shall be conforming with the new Belgium law for non-profits organisations called the Companies and Associations (CAC). Therefore, we started to look into our statutes to amend as necessary to be compliant to the new law.

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Members were invited to join this subgroup to discuss changes in the statutes that would help the development of ADHD Europe. The subgroup started their work after the AGM in 2021, looking at other changes that would be helpful for the development of ADHD Europe. We met several times and proposed a first draft to the board which was discussed. These amendments were sent to our member organisations and we invited them again to join the statutes working group. All member organisations were requested to provide input at two virtual meetings. Members who attended discussed finalizing the draft which took place in November and December. This draft had been sent to a lawyer for review and was approved by the members at the AGM 2022 in Cyprus.

After the AGM we wanted to get the revised Articles of Association legalized, but the Notary Public told us that for changes in Art. 2 we need a Royal Decree (which takes a long time) and for the changes in Art. 4,5 and 7 this has to be done at an AGM or EGM with the attendance of a Notary Public. At that time the AGM was already planned in Helsinki - therefore we proceeded with a suggestion for a possible procedure to the members.

### BROADCASTING ADHD EUROPE COMMITTEE

**Lead: Hans van de Velde** (January 2022 until September 2022) **and Nina Hoven** (October 2022 until September 2022)

Supported by: Beatrice Blackett, Nina Hovén, Andrea Bilbow, Viljo Wilding, Vilhjálmur Hjálmarsson, Richard Sullivan, Chantel Fouche,

Both Hans van de Velde and Nina Hoven organized many online webinars with co-ordination with the two committees broadcasting/communication by giving technical help and dissemination on the social media platforms.

Hans van de Velde was the organiser of the online mini-congress during our face-to-face AGM 2022 in Cyprus with the co-ordination with the communication's committee for dissemination. These five videos are available on our youtube channel.

Nina Hoven took over Broadcasting ADHD Europe subcommittee before October Awareness month from Hans van de Velde. All the content is available on the below link.

Members of ADHD Europe were invited to participate in webinars during ADHD-awareness month to share best practices and share experiences.

These videos are available on the Youtube channel which was restructured by Hans van de Velde for easier access to each related webinar topic.

<https://www.youtube.com/@BroadcastingADHDEurope>

Overall, our YouTube channel under the branding "Broadcasting ADHD Europe" runs well. we have 3,870 subscribers on Youtube.

## **SURVEYS AND RESEARCH COMMITTEE**

### **Lead: Carola Stivala**

Members: Rob Pereira (The Netherlands), Lia Stampoltzis (Greece), Stephanie Clark (UK) and Joanne Norris (Belgium/USA)

Volunteers welcome to join the committee! Meetings held either on a Monday or Tuesday - 3rd week of the month from 7.30-9pm by Zoom

The committee has been working on produced materials

- Library of Scientific Research information links about ADHD for placement on the website ("living document"- to be periodically reviewed by the Professional Board)
- ADHD Medication Information Brochure: "The experience-expert that (will be) you!" - author Dr. Rob Pereira ( for dissemination/ adapt to country context)
- "The Future of ADHD in Europe" Webinar with Prof. Tobias Banashewski on May 2022 via 'Broadcasting ADHD Europe' on youtube. [https://youtu.be/HpO\\_McNYt\\_o](https://youtu.be/HpO_McNYt_o)

Carola Stivala attended, represented ADHD Europe and presented "The ADHD-Europe Survey 2020" on

- 20 June 2022 - (live) at the European Society of Child and Adolescent Psychiatry (ESCAP) Symposium entitled "ADHD - The Patient's Perspective", Eindhoven, The Netherlands
- 22 Sept 2022 - (online) Presentation of for the Macedonian Academy of Sciences and Arts, and the North Macedonian Association for ADHD, Skopje, North Macedonia.

The committee is currently working on:

"ADHD & Education" Survey (researcher or student volunteers wanted!)

- Update of Survey 2020 with our new members
- list of ADHD topics to suggest to researchers / for projects
- webinars on topics & with our members (collaboration with communications committee 2023-2024)

ADHD Europe were invited to present the 'Access to Diagnosis & Treatment' Survey in French of which is also available on our website in French. Chantel Fouche travelled to Montpellier, France on the 22nd June 2023 to present survey which was a parent & public event attended by 200 people. The 23-24th was the Colloque International that was held in a large auditorium with over 1000 people or more and topic related workshops were held over the 2 days as well. ADHD Europe had a table in the visitors area where we displayed our pamphlets and roll-up. Our member organisations were also there, TDAH-France, TDAH Paca, ASPEDAH and AIFA. Dr. Dora Wynchank gave the opening presentation on the 23rd, and kindly spoke about ADHD Europe/ADHD Awareness Month activities and the ADHD Women Project at the end of her presentation about ADHD in Women. [More information](#)

## **SOCIAL MEDIA & COMMUNICATIONS COMMITTEE**

**Lead: Nina Hovén-Korpela**

Supported by the board and members, Vilhjálmur Hjálmarsson, Hrannar Arnarsson, Chantel Fouche

The role of the social media committee is to communicate the work we are doing to create awareness and advocate on European level with collaborative partnerships in various projects.

Our goals including spreading evidenced based information, breaking myths with facts, reducing stigma and discrimination for people living with ADHD. We are on the pathway to do this with our members and global community!

**Website** [www.adhdeurope.eu](http://www.adhdeurope.eu)

Updates on our website are ongoing with discussions within our various subgroups. We are happy that our members submit content for us to feature on the website. The website has been refreshed from free software which had limited capabilities and now it allows better visitor experiences with an enhanced professional structure. Content updates on our website are ongoing with discussions within our various subgroups.

We invite members to submit content for us to feature on the website or send us your ideas to [communications-committee@adhdeurope.eu](mailto:communications-committee@adhdeurope.eu). We are happy that our members submitted content for us to feature on the website for their October 2022 events including our work with partnerships with researchers and other organizations in Europe.

**Twitter** [www.twitter.com/ADHD\\_Europe](https://www.twitter.com/ADHD_Europe)

As of February 2023, our twitter account has 4,602 followers. We regularly tweet information about our work and about the research projects we are a part of, and we use this platform to promote our members by retweeting content.

## **Facebook**

We maintain our two Facebook groups and public Facebook page. Our Facebook page has 4,600 followers as of February 2023  
[www.facebook.com/adhdeurope](https://www.facebook.com/adhdeurope)

Our private Member Organisations' Facebook group has 135 members.

Our public Facebook group which anyone can join has 5,562 members from all around the world (This group is moderated by four admins to prevent malicious posts. Most of our followers are women.  
[www.facebook.com/groups/ADHDEurope](https://www.facebook.com/groups/ADHDEurope)

**Linkedin** [www.linkedin.com/groups/2310293](https://www.linkedin.com/groups/2310293)

Linkedin has 4,149 followers who are mostly professionals who share information we post, or information they find relevant, or network. We more people daily who are interested to join, share and comment.

## **Newsletter**

During 2022, we issued various newsletters with news after our AGM, research information, invitations to European events, before and after broadcasting on youtube, October Awareness Month information and sent holiday season greetings over the festive period in December.

**Email** [info@adhdeurope.eu](mailto:info@adhdeurope.eu)

The communication team has answered to lot of emails where people ask help, support or advice on our general email address. Due to the influx of requests for individual help. We have encouraged people to contact our member organisations in Europe for help and we have put a notice on the website that reflects that we do not assist people individually.

## **Link.tree**

We currently have three accounts

ADHD Europe [www.linktr.ee/ADHDEurope](https://www.linktr.ee/ADHDEurope)  
ADHD Women [www.linktr.ee/ADHDWomen](https://www.linktr.ee/ADHDWomen)  
ADHD Living Library [www.linktr.ee/ADHDlivinglibrary](https://www.linktr.ee/ADHDlivinglibrary)

This online tool helps share everything we create, curate, easy access to all social media profiles and to help society to find all the information with the work we do.

## **IT-structure**

2022 ADHD board decided to make a contract with a Finnish IT-company Tahto Group to admin Europe's IT and build up a structure for SharePoint/Teams.

## **COACHING COMMITTEE**

**Lead: Carola Stivala** (from October 2022 – before Hans van de Velde)

Group members are: Beverley Nolker, Linda Fox, Marie Enback, Agnes Hajdu, Monica Conversaro, Beverley Sinton, Trish Nymark, Sigrún Jónsdóttir, Alison Clink Zerouk, Ute Kögler, Christina Sarantopoulou, Joanne Norris, Alexia Hetzel, Harriet Andriessen

The committee continued discussion about what coaching of people with ADHD is and should be. The exchange of experiences about coaching methods is most appreciated.

The work on Version 2 of the Practical Guide took a lot of energy; it was finalized in 2022.

<https://adhdeurope.eu/adhd-coaching-a-practical-guide-2022/>

The plan was discussed to organise a few webinars on the different coaching approaches; to be realised in 2023.

## **ADHD AWARENESS MONTH COMMITTEE**

**Lead: Nina Hoven**

Supported by members are from Belgium, Iceland, Finland, Spain and United Kingdom

The theme for Awareness Month 2022 was 'Understanding a Shared Experience' which was in collaboration with ADHD Awareness Month who is our partner to join America and Europe together. We held several member meetings with members, and we decided to share experiences under the theme "Talking Thursdays". This was an opportunity for members to submit videos to share their knowledge and experiences about diagnosis & treatment in their countries. We also hosted two live webinars streamed to the public on social media with professionals. All the information can be found here <https://adhdeurope.eu/adhd-awareness-month/>

## **ADHD DAY in NETHERLANDS "THE POWER OF ADHD?"**

**Lead: Hans van de Velde, Myriam Bea and Rob Pereira (NL)**

Supported by members of the Board

Preparations for this event started in October 2021 and the event took place on the 14<sup>th</sup> October 2022, in Leiden, Netherlands.

Leiden 2022 'City of Science' with a 365-day program of which we selected the 'ADHD Day' on the 14<sup>th</sup> for all who are curious and we created the motto:

"The Power of ADHD" – to show that ADHD is not only a disability but also seen as a condition with different strengths and weaknesses compared to people without ADHD.

The program was very diverse to showcase ADHD, creativity, fantasy with interviews and interactive sessions with experts in the field of ADHD as 'Science makes our minds wonder!'

Speakers on various aspects had their say, with classic lectures alternating with discussions and interactive talk shows. ADHD Europe used the opportunity to create more awareness and talk about the work we do. The event was held at the Leiden university in the Amphitheatre with participants at the venue and was also held online.

Guest speakers were very well organised by Hans van de Velde.

Only humans can imagine the Future with Jacques Verraes LL.M. (Directorate-General for Research and Innovation at the European Commission) was the opening speech with a combination of lecture and interviews with young people on the topic "Creativity versus medication? Cooperation between you and your doctor".

Lessa Schippers and Martine Hoogman provided information on "Qualities of ADHD, the positive sides. Imagine being a researcher". Afterwards, Marianne Schulpen, Guus Lustig and Nicholas Cointepas spoke as employers and employees on the topics: "Can I profit from ADHD strengths as an employer?" and "Do I tell my employer about my ADHD as an employee?"

Focus on ADHD Women Health Research – Blurring the borders between living experience and clinical expertise'with Prof. Sandra Kooij & Bethan Burnside PhD

In a rather innovative way Bethan Burnside presented the latest news from ADHD research, followed by ex addicts with ADHD sharing their story.

During lunch and coffee breaks, speed coaching was offered. At the same time there was also the "Living Street Library" outside located at the nearby train station, we had a tent, with various posters promoting the Living Library and creating awareness of ADHD. People could come there to talk more about ADHD and find out more information. We created an online Living Library with booklists for children, teenagers, adults, women and beginners guides to ADHD. <https://linktr.ee/adhdlivinglibrary>

## **ADHD AND WOMEN COMMITTEE**

### **Lead: Chantel Fouche**

Supported by various ADHD Europe members (organisational, professional, individual & honorary), Dr. Kate Carr-Fanning, Professor Sandra Kooij (members of the Professional Advisory Board)

The Knowing Me! Knowing You (KMKY) Peer to Peer support groups have been running since May 2021 and continue with much appreciation by ourselves ADHD Europe for the administrative work by our organizational member (ADHD, ASC & LD Belgium), and the facilitation of these meetings by Joanne Norris, Ed.D. (Honorary member), and Donnalea Barber (professional member) of ADHD Europe.



Campaign activities continue and the social media channels are well received by the public to raise awareness, and a space for women to interact on common experiences. The followers for each communication channel is [Facebook](#) (16k), [Twitter](#) (2.4k), [Instagram](#) (10k) and [Linkedin](#) (1k). A linktr.ee account was also opened to display all information and activities by the ADHD Women Project <https://linktr.ee/ADHDWomen>

The website is continually updated by volunteers including various member contributions for translations of the static text which is the base of evidenced information written by Joanne Norris, Ed.D. in 2020. A very big thank you to all members who have been translating the text for the website [www.adhd-women.eu](http://www.adhd-women.eu).

### **Member Involvement – ADHD Women & Gender Equality**

The ADHD Women project held several meetings to involve members in discussions about research, sharing experiences & and knowledge and raise awareness by sharing best practices. These activities include

1. **Creating resources** with the goal to produce future ISBN books. The text and ideas to create this is work in progress within the respective working groups that are member-led groups by
  - Our Honorary member, Stephanie Clark, Lead of 'Menopause & Beyond' working group
  - Board member of our member organization, Impuls & Woortblind, Saskia Elswijk, Lead of the 'Burnout' working group
  - Our professional member, Patricia Vasu, Lead of the 'Executive Functioning' working group
  
2. **Participating in Research** - During 2021, ADHD Europe representatives participated in focus groups to discuss with Prof. Sandra Kooij and Dr. Dora Wynchank for the creation of the survey 'Health of women with ADHD, incl. hormones and cardiac health'. Due to Ethics approval and sensitive contents of the survey the release date is unknown but hopefully will be ready in 2023 for the public.

During 2022, members were invited

- a) to join focus groups with our Professional Advisory board member, Dr. Kate Carr-Fanning who started phase 1 of the project entitled 'ADHD Woman and their Wins: A study of empowerment enablers in education and employment'
- b) by Ailbhe McKinney (PhD Researcher) and her supervisor, Sinead Rhodes (Senior Research Fellow from the University of Edinburgh, Scotland,) to attend focus groups about Psychoeducation Intervention for Children and Young People (EPIC). More information on [Youtube](#)
- c) met with the Women's Brain Project on various occasions to discuss research which affects all women with all health conditions. More to follow in 2023 with developments that are envisaged to collaborate on future exciting projects.

### 3. Raising ADHD Awareness

ADHD Europe members were given the opportunity to ask their male & female members and network to provide videos in their language to share their individual experiences. The new Youtube channel was launched in October 2022 during Awareness Month and is called

“Sharing Experiences – Awareness & Advocacy”

<https://www.youtube.com/@sharingexperiences-adhdawa6347>

Since 2021, ‘Let’s talk ADHD’ based in Hong Kong has been inviting the ADHD Women Project to share experiences and best practices. In 2021, Chantel Fouche gave a presentation called ‘Whoa! What Happened? Outlining how in the last year the ADHD Women Project has progressed and giving information about ‘Gender Equality’ from evidence-based information provided by experts in the field of ADHD.

To celebrate ADHD Awareness Month, experts in the field of ADHD held a combined webinar sharing their knowledge and experiences <https://www.youtube.com/watch?v=n6ujPhwKhTw&t=66s>

- a) **‘Impact of ADHD at work, in families, relationships and sexuality’** presented by Dr. Dora Wynchank. This talk will explore some intimate areas in the life experience of women with ADHD. What characterises their relationships, and their sexual experience? In a couple when one member has ADHD, what is the impact on the relationships? We will discuss the research on whether sexual problems or gender identities are affected by having ADHD. Finally, we will look at some of the sequelae of having untreated ADHD in the workplace.
- b) **‘Positive Disruptors: ADHD Women and their Wins’** presented by Dr. Kate Carr Fanning who talks about the need to provide opportunities for empowerment for woman with ADHD, preliminary findings from a recent study with woman with ADHD identifying empowerment enablers in education and employment focusing on what educators, employers, woman themselves and others working with them can do to enable the empowerment of woman with ADHD.
- c) **‘How am I empowered?’ and ‘Gender Equality’** Chantel Fouche lead of ADHD Women Project (ADHD Europe) with be #sharingexperiences of empowering herself and others by raising awareness globally. She will share what ‘Gender Equality’ means to her and how society can help combat stigma & discrimination for all ADHD men and Women, their families, and carers. ‘Everyday is ADHD Awareness Day’

#### **4. Advocating Mental Health & Gender Equality for Men/Women towards access to proper care & treatment**

With thanks to EFNA (European Federation of Neurological Associations), The ADHD Women have been included with EFNA's network to work together as one voice towards the 'Sustainable Development Goals (SDG) 5: Achieve gender equality and empower all women and girls, and the European Parliament's Committee on Women's Rights'. Chantel Fouche represented members at various meetings

- a) Sharing her personal experience at an award ceremony for winning an award for her efforts as an individual in the development and promotion of advocacy for people with ADHD, 'Advocating for Gender Equity in Neurology'. [More information](#)
- b) Speaking at the 'Addressing Gender Equity in Neurological Care' about the differences of ADHD in men & women. Results of the survey "Assessing diagnosis and care pathways of people living with neurological disorders" was also shared during the webinar. [More information](#)
- c) Participating at the MEP Interest Group (Brain, Mind, Pain) at European Parliament about 'Addressing gender-related issues and bias in the prevention and treatment of neurological conditions'. [More information](#)

## **PARTICIPATION, REPRESENTATION, AND ENGAGEMENT**

Our various subcommittees have participated & represented ADHD Europe, engaging with various stakeholders. See above subcommittee reports. There have been many activities in Europe including

**The World Health Organisation** held two information consultations of which ADHD Europe were invited to join on 18 and 19 May 2022. WHO is committed to supporting the meaningful engagement of people living with noncommunicable diseases and mental health conditions (PLWNCDs and MHCs) worldwide. As part of this work, the WHO Global Coordination Mechanism on NCDs (GCM/NCDs) has engaged with PLWNCDs and MHCs to better understand and learn from individuals with lived experience to co-create NCD and mental health policies, programs and services.

WHO GCM/NCD Secretariat and the WHO Regional Office for Europe invited ADHD Europe to represent our members at an online meeting entitled WHO Informal Consultation with People Living with Noncommunicable Diseases (PLWNCDs) and Mental Health Conditions (MHCs) in the European Region that took place on 18 and 19 May 2022. ADHD Europe had to complete a Declaration of Interest as WHO Expert to be able to join the meeting. We were accepted to be part of the meeting, and WHO forwarded us the concept note and participation guide to explore and support the co-development of a new WHO framework. ADHD Europe participated in discussions about meaningful engagement across the two days representing the voices of people living with ADHD and. Recordings are available on youtube [Day One](#) and [Day Two](#).)

## **European Memberships**

Chantel Fouche attended three Annual General Meetings during 2022 representing ADHD Europe either online or face-to-face in Brussels

### **1) EFNA (European Federation of Neurological Associations)**

ADHD Europe support the [Book of Evidence](#) Mandate 2019-2024 which is very much applicable to the advocacy work we do as an initiative of EFNA with the Brain, Mind, Pain MEP Interest Group. The three themes are

- [Eradicating Stigma, Isolation and Discrimination](#), our participation reaches back to 2019 presenting at the World Brain Day event.
- [Access to Diagnosis and Support](#), we have been attending various focus group meetings with regards to the Pathways to Care, discussion the challenges before and after a diagnosis for all people living with ADHD.
- [Patient Empowerment for Increased Involvement and Engagement](#), through the ADHD Women Project, we have been advocating to high level stakeholders and policymakers about ADHD, including raising awareness to empower those living with ADHD.

2) **Gamian Europe** - Chantel Fouche has been sharing best practices from the women project peer to peer support groups to help support Gamian Europe's 'peer support project' project to reach stakeholders to help in the development of the digital resource centre. More information to follow in 2023.

3) **Mental Health Europe** gave ADHD Europe the opportunity to share our experiences and share informative knowledge about 'Stigma & Discrimination' for people living with ADHD to many European Mental Health organizations. Myriam Bea and Chantel Fouche presented at the webinar event held on the 29th April 2022.

## **European Stakeholders**

In Brussels, Chantel also attended various stakeholder meetings (policymakers, WHO representatives, national brain councils, neurological patient organisations etc.) to raise more awareness of ADHD. These meetings were also attended by EFNA, Gamian Europe or Mental Health Europe. These meetings/conferences which were face-to-face giving an opportunity to promote ADHD Europe and the ADHD Women Project with marketing material and pamphlets at

European Health Summit

<https://www.euhealthcoalition.eu/eu-health-summit/>

Brain Innovation Days Conference

<https://www.braininnovationdays.eu>

Policy Debate at the European Committee of Regions

<https://www.euregha.net/event/cor-interregional-group-on-health-and-wellbeing-towards-a-european-strategy-on-mental-health/>

## RESEARCH PROJECTS

ADHD Europe involvement with research projects in 2022 with

1. one university research project R2D2-MH
2. the continuation of projects as reported in previous year's Annual Reports
3. research consortia to contribute to proposals for future funding as an official partner

All research information is kept up to date on our website

<https://adhdeurope.eu/research/>

The Communication Committee has been active following research projects and disseminating research information on our social media channels.

### 1. PARTNERSHIPS WITH UNIVERSITIES

Antwerp University (based in Belgium) are official partners of the R2D2-MH (Risk & Resilience in Developmental Diversity and Mental Health) Project and has included ADHD Europe within their budget. This opportunity gives us as a European umbrella organization to share patient voices for all communities by participation in the cocreation groups in collaboration with researchers and project partners. These groups have the involvement of young people and adults with neurodevelopmental diversity. More information below.

#### R2D2 - MH PROJECT [www.r2d2-mh.eu](http://www.r2d2-mh.eu)

R2D2-MH Project (Risk & Resilience in Developmental Diversity and Mental Health) started in late October 2022 and has an end date of August 2027. Antwerp University based in Belgium who are collaborating ADHD Europe as described below with aims and involvement.

The project has received funding from the European Union's Horizon Europe research and innovation programme under grant agreement GA 101057385. R2D2-MH's four main ambitions to progress beyond the state of the art:

1. Provide the largest European multi-scale dataset on early human brain development and MH outcomes
2. Identify biological mechanisms of resilience to reduce the adverse effects of NDD
3. Co-develop, with the stakeholders, new digital tools to increase participatory research/medicine and reduce stigma
4. Establish predictive models to guide personalised interventions

Nina Hoven is the lead on this project representing ADHD Europe and our role in this project is to attend various meetings and workshops to

1. share the patient voices and experiences of the communities we represent to researchers, and partners involved in the R2D2 project

2. participate in the cocreation groups to with the involvement of young people and adults with neurodevelopmental diversity working towards the development of the CareConnect portal.
3. dissemination and communication on our social media platforms
4. including efforts to reduce stigma and burden for individuals with Mental Health conditions. €600 billion per year 38,2% of the EU population

## 2. PARTNERSHIPS WITH OFFICIAL PARTNERS

During the first half of the year, Hans van de Velde represented ADHD Europe and the second part of the year Nina Hoven & Chantel Fouche represented ADHD Europe giving input for three projects of which our member organization, ADDISS was partner. We joined several meetings both face to face and online. ADHD Europe contributed during these meetings by sharing experiences and knowledge about the patient voice for people living with ADHD. When research was available, we assisted in dissemination activities by sharing information on our European communication channels (newsletter, social media and website). More information below about each project.

### THE EAT2BENICE PROJECT <https://newbrainnutrition.com>

The Eat2BeNice Project started in on 1 September 2017 with an end date on 28 February 2023. Funding for this project was awarded via the European Union's Horizon 2020 research and innovation programme under the Grant agreement ID: 728018.

Eat2beNICE combined the expertise of 18 partners around Europe with the aims to (1) to identify nutrition and lifestyle drivers that can be employed to prevent detrimental impulsivity/ compulsivity in males and females across the lifespan (2) to characterize the etiologic paths leading to extreme behaviour (3) to promote policy changes to counteract maladaptive impulsivity/compulsivity by disseminating evidence-based information about health-related behaviours to families, clinicians, policy makers, and general public.

During the project duration, ADHD Europe gave input as described below with our member organisation, ADDISS and assisted in dissemination activities by sharing information on our European communication channels and more.

Board members were invited join the online meetings and final project Annual General Meeting was held in Malta, in January 2024 of which Nina Hoven represented ADHD Europe. The outcomes of the project was an online cookbook. On the website (link above) you will be able to find

Online cookbook to download (practical tips, recipes, background information and videos)

Educational talks by Eat2beNICE experts / researchers from various universities and Dr. Alejandro Arias Vásquez on the link between the gut and the brain.

An easy-to-follow dictionary to quickly learn the list terms about New

Brain Nutrition when it comes to anxiety, brain health, compulsivity, impulsivity, supplements, microbiome, Mediterranean Diet, Elimination Diet, micronutrients and more .../

An easy-to-follow dictionary to quickly learn the list terms about New Brain Nutrition when it comes to anxiety, brain health, compulsivity, impulsivity, supplements, microbiome, Mediterranean Diet, Elimination Diet, micronutrients and more .../

Blogs written by researchers and early career researchers

Cooking for your brain by the Celebrity Chef and Nutritionist Sebastian Lege with easy-to-do recipes with nutritional tips to live a healthier life, both mentally and physically

## **CANDY PROJECT** [www.candy-project.eu](http://www.candy-project.eu)

The Candy Project started on 1 January 2020 with an end date of 31 December 2024. Funding for this project was awarded via the European Union's Horizon 2020 research and innovation programme under the Grant agreement ID: 847818.

The project is coordinated by Radboud University (Medical Centre) in Nijmegen, Netherlands. The project investigates the biological links between these neurodevelopmental disorders and co-occurring somatic illnesses and how treatment and monitoring of affected patients can be improved.

Nina Hoven gave a 'MasterClass' presentation remotely during the General Assembly for Early Career Researchers held in Paris in January 2024. The presentation was about how scientists speak to patients and giving tips on better communication strategies that could be used for dissemination materials. Andrea Bilbow spoke about the challenges of raising children with ADHD and autism especially when parents themselves have the conditions.

ADHD Europe's role in the 'Candy' project is attending various workshops and annual partner meetings (face-to-face and online) when research was presented with outcomes to all project partners. The project's multi-disciplinary team of world leading academics SMEs are currently working on the following to

1. identify novel mechanisms underpinning NDDs and their multi-morbidity
2. develop new strategies for prevention and treatment
3. deliver novel biomarkers to guide early diagnosis, stratification and/or treatment monitoring
4. provide open-access databases, translational test batteries, and tools and targets for valorisation.

## **TIMESPAN PROJECT** [www.timespan.eu](http://www.timespan.eu)

The Timespan project started on 1 April 2021 with an ending date of 31 March 2026. Funding for this project was awarded via the European Union's Horizon 2020 research and innovation programme under the Grant agreement ID: 965381.

The Timespan Project aims to advance the management of patients with attention deficit hyperactivity disorder (ADHD) and co-occurring cardiometabolic disease by improving available treatments and risk stratification. The two conditions share substantial comorbidity and common genetics, with cardiometabolic disease leading to premature deaths and placing a substantial burden on healthcare systems. Moreover, the co-existence of psychiatric disorders in patients with this profile cannot be overlooked. The project's work is expected to improve the clinical outcomes as well as the quality of life of adult ADHD patients with co-occurring cardiometabolic disease.

Hans van de Velde, Nina Hoven and Chantel Fouche attended various online meetings. Hans van de Velde & Nina Hoven were both invited to give presentations at the face-to-face General Meeting in Stockholm in May 2022. Viljo Wilding and Andrea Bilbow also gave presentations at the meeting.

ADHD Europe disseminates information when and results of the research upon publication by the partners. There are opportunities for ADHD Europe to join scientific conferences which are platforms for TIMESPAN talks, posters and symposia (Eunethydis, ECNP, World Congress on ADHD, World Congress of Psychiatric Genetics, European Congress on Obesity, European Society of Cardiology congress, UK Adult ADHD Network, International Conference on Pharmaco-epidemiology & Therapeutic Risk Management, Asian Conference on Pharmacoepidemiology, International Society of Pharmacovigilance).

## **FUTURE PLANS**

### **TAKING ADHD EUROPE TO THE NEXT LEVEL**

The Board intends to continue their current strategies of building a strong organization and membership that has a voice for people with ADHD. This is done by listening to its members and wherever possible financially or otherwise act on their suggestions.

The Board continues its efforts within our membership to build a stronger infrastructure, better communication tools, promoting and increasing membership, active involvement in projects and events. We would like to thank our active members who participate in our different subcommittee groups and hope to encourage more participation from members.



## MEMBER ORGANISATIONS IN 2022

- ADAPT (Austria)
- ADDISS (UK)
- ADD-ADHD Cyprus (Cyprus)
- ADHD, ASC & LD Belgium (Belgium)
- ADHD Felagið (Faroe Islands)
- ADHD Foreningen (Denmark)
- ADHD Hellas (Greece)
- ADHD Ireland (Ireland)
- ADHD Liitto Ry (Finland)
- ADHD Malta (Malta)
- ADHD Norge (Norway)
- ADHD Samtökin (Iceland)
- ADHD Solutions CIC (UK)
- ADHS Deutschland e.V. (Germany)
- ASPEDAH (Switzerland)
- A.I.F.A. Onlus - Associazione Italiana Famiglie ADHD (Italy)
- Buđenje – Udruga za Razumijevanje ADHD-A (Croatia)
- Dundee & Angus ADHD Support Group (UK)
- Elpos Schweiz (Switzerland)
- FEAADAH (Spain)
- Fundacion ADANA (Spain)
- Hypersupers TDAH France (France)
- Impuls & Woortblind (Netherlands)
- Juvemus e.V. (Germany)
- O Kyriakos (Greece)
- Palfoldi Public Benefit Foundation (Hungary)
- Rainbow Warriors Mavrični Bojevniki (Slovenia)
- Riksförbundet Attention (Sweden)
- TDAH PACA (France)
- Treffpunkt ADHS (Luxembourg)
- Vomojotsvet (North Macedonia)