

ANNUAL REPORT FROM THE BOARD (2021)

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.

Today, ADHD Europe represents 21 European countries comprising of 32 organisational members, 21 professionals & 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 ADH 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.

STRUCTURE, GOVERNANCE, AND MANAGEMENT

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

The 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 2021 there were over 20 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 in September 17th to 21th in Rotterdam, Netherlands.

The Board in 2021

President

Dr. Myriam Bea (Elected June 2020)

Vice Presidents

Hans van de Velde (Elected April 2021)

Andrea Bilbow (Elected June 2020)

Secretary

Christina Georgiadou (Elected June 2020)

Treasurer

Chantel Fouche (Reelected April 2021)

Ordinary Board Members

Nina Hovén-Korpela (Elected April 2021)

Carola Stivala (Relected April 2021)

Viljo Viiding (Elected April 2021)

Hrannar Björn Arnarsson (Elected June 2020)

Professional 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 2021

Prof Sandra Kooij

Prof Philip Asherson Dr

Dr Anthony Ramos

Prof Barbara Franke

Prof Tobias Banaschewski

MD PhD Dr Susan Young

Dr Kate Carr-Fanning

You can find out more about our board members at

<https://adhdeurope.eu/about/meet-the-board/>

and about our professional advisory board members at

<https://adhdeurope.eu/about/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.

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 has been sent to a lawyer for review.

The Board follows the Policy Handbook for Volunteers who join our board and use our IT systems.

Broadcasting ADHD Europe Committee

Lead: Hans van de Velde & Viljo Wilding

Members: Beatrice Blackett, Nina Hovén-Korpela, Andrea Bilbow, Chantel Fouche

The webinars are organised by Hans van de Velde who is the host and interviews speakers. Viljo Wilding takes care of the technical formalities during the broadcasting. The webinars-branding “Broadcasting ADHD Europe’ works excellently. During 2021 there were 13 webinars on our YouTube channel (± 25.000 views)

<https://www.youtube.com/c/BroadcastingADHDEurope/videos>

Our efforts are much appreciated by our members, people with ADHD, general public and experts in the field of ADHD including scientists. During ADHD-awareness month we even had a webinar every week.

Surveys and Research Committee

Lead: Carola Stivala

Members: Rob Pereira, Lia Stampoltzis, Stephanie Clark, Joanne Norris, Hans van de Velde, Chantel Fouche, Myriam Bea and Christina Georgiadou.

Produced materials:

- Library of Scientific Research information (links) about ADHD (reviewed by professional board) for on the website (“living document”)
- Member Organisation Survey (webinar interview style – Hans and Carola 2022/ 23)
- “ADHD & Education” Survey (researcher wanted!)

Working on:

- updated article about ADHD & Driving (Stephanie Clark & Joanne Norris) - database of European educational resources about ADHD (in different languages) for website
- list of ADHD topics to suggest to researchers / for projects
- list of EU organisations involved with ADHD (for our CRM database)
- list of European researchers and projects specializing in ADHD (for our CRM database)
- Collaboration with Organisers of “ADHD DAY” – 15 Oct. 2022 Leiden

Volunteers welcome!

Social Media & Communications Committee

Lead: Nina Hovén-Korpela

Supported by Viljo Wilding, Andrea Bilbow, Hrannar Arnasson, Christina Georgiadou, Chantel Fouche and other members

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. We would like to share your activities too on social media. Please tag us, or contact us, so that we can reshare your information and activities on social media. 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

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

Twitter

As of February 2022 our [twitter](#) account has 3,985 followers.

Facebook

We maintain our two Facebook groups and public Facebook page. Our [Facebook page](#) has 4,070 followers as of February 2022. Our private Member Organisations' Facebook group has 116 members, and our public Facebook page which anyone can join has 5,200 members from all around the world.

Newsletter

During 2021, we issued various newsletters after our AGM, before webinars, October Awareness Month information and sent holiday season greetings over the festive period in December.

Coaching Committee

Lead: Hans van de Velde & Carola Stivala

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

One of the important subjects was: What is ADHD-coaching? What should it be and what standards would we want? We exchanged experiences about coaching methods.

Furthermore, we explored resources for funding of coaching courses. We have been digging into the so called Erasmus+ EU funding. This inspired us also to make a start with looking into the possibilities of funding of a so called strategic parentship of our members with for instance scientific institutes to work on innovation. Version 2 of the Practical Guide for finding a coach for your ADHD came online. [Click here for the PDF with the guide](#)

The new subjects for discussion are:

- Developing vision on Multidisciplinary treatment including coaching.
- How can ADHD-Europe stimulate more professional adequate coaches in Europe?

ADHD Awareness Month Committee

Lead: Nina Hovén-Korpela
Supported by Chantel Fouche

The ADHD Awareness committee, represented ADHD Europe and our members as a partner with the global coalition by preparing resources online for the annual ADHD Awareness Month campaign.

Videos from experts and professionals were released on the webpage such as Melissa Orlov, Prof. Samuele Cortese, Dulce Torres, Dr. Thomas Brown, and Dr. Faye Dixon on a diverse range of topics, including relationships, treatment plans, parenting, co-occurring conditions, and diagnosis in children and adults.

You can get the latest information on the ADHD Awareness Month website <https://www.adhdawarenessmonth.org/> and you can sign up for their mailing list to get more information.

ADHD Day - 15 October 2022 Leiden “Fantasy”

Lead: Hans van de Velde, Myriam Bea and Rob Pereira

Hans van de Velde and Myriam Bea for ADHD Europe & Rob Pereira on behalf of Impuls & Woortblind (NL) plus board members and members from the Netherland organization are busy organizing this event.

We succeeded in claiming our own day in this European City of Science year in Leiden.

In 2021, preparations began. We started with making a program for this grand event, finding young potentials who want to e.g. do their study thesis for our event, and we already have some top-speakers.

ADHD and Women Committee

Lead: Chantel Fouche

Supported by various organisational, professional and individual members

We have so much information to report about the ADHD Women Project which has gone international!

Dating back to 2020, our member organisations (ADHD, ASC & LD Belgium AISBL and ADHS Deutschland e.V.) joined forces under the EFNA #brainlifegoals funding grant. A website was built www.adhd-women.eu in English and German, which to-date has over 15k views of which 3k views were in October 2021 during ADHD Awareness month.

Campaign activities continue on the webpage with [personal stories](#). Raising awareness on social media which has grown exponentially with followers from [Facebook](#) (11k), [Twitter](#) (1.6k), [Instagram](#) (4k) and [LinkedIn](#). In May 2021, to continue making a difference in the lives of women with/without ADHD, Joanne Norris, Ed.D. (Honorary member), and Donnalea Barber (professional member) offered to facilitate ‘Knowing Me! Knowing You (KMKY) [Peer to Peer support groups](#)’. These meetings are attended by women around the world. Since June 2021 monthly newsletters are sent to over 900 subscribers.

In addition, ADHD Europe were thrilled to start the ADHD Women subcommittee group in 2021 to continue our efforts across Europe with our members, to share ideas, knowledge and experiences. We will be rolling out different languages on the website with volunteers who are able to translate so that women have a place to go to get reliable information. During October Awareness Month our members formed working groups to shine a light on ADHD Women.

Numerous webinars have been broadcasted including 'Women, ADHD and Hormones', 'ADHD & Sleep' plus the exciting news about new research survey looking into insights on 'Health of women with ADHD, incl. hormones and cardiac health' which will be released shortly by Prof. Sandra Kooij (professional advisory member) and Dr. Dora Wynchank (professional member). [Read more...](#)

Our efforts for best practices and advocacy has taken the project to new heights in 2021. The [ADHD Care Project](#) in partnership with the Serbian and Belgium Brain Councils invited us twice to be speakers. Chantel Fouche flew to Thessaloniki, Greece in July and invited again to join their online conference streamed from Cyprus in September. 'Let's talk ADHD' from Hong Kong also contacted us to raise ADHD awareness for the Chinese communities by speaking at their conference.

On 19 October, our best practices were showcased during a five minute presentation at the 'Annual MEP Interest Group Brain Mind Pain Meeting' engaging with policymakers & high-level stakeholders for more decision-making for women with the support of MEP Frances Fitzgerald (Ireland, EPP Political Group). You can see this short presentation on [Youtube](#) (fastforward to 2h14, MEP Frizgerald at 2h08). We informed participants about the lack of education, funding and understanding about ADHD. This opened up more communication channels with neurological patient organisations and stakeholders to engage more with us to collaborate or disseminate our efforts to amplify our ADHD voices in 2022.

ADHD & LGBTIQA+ Committee

Lead: Viljo Wilding & Hans van de Velde

We have started preparations to form a new committee on ADHD & diverse sexual orientations and gender identities, short: ADHD & LGBTIQA+. Volunteers welcome!

Neurodiversity

Lead: Myriam Bea

Group participants are Joanne Norris, Johannes Streif, Marko Ferek, Isabel Rubio and Hans van de Velde. This year due to lack of time there is no progress. Work to be continued and more volunteers welcome to join these discussions.

Aims and Objectives Committee

Lead: Myriam Bea

Supported by the whole board

This committee pretty much dissolved in monthly board meetings and board members continue taking various actions. Due to Covid restrictions ideas and plans couldn't be implemented. Work is ongoing and we will keep you posted.

PARTICIPATION, REPRESENTATION, AND ENGAGEMENT

2021 has been challenging for all due to the Covid epidemic. Where possible the members of the board have been for the ADHD voice by-collaborating, sharing and networking with our European Network. Being an ambassador for ADHD Europe is a great privilege and our board members are grateful for the opportunities they have to attend events and promote ADHD Europe's work.

The 8th World Congress on ADHD was held during 6-9th May 2021. Carola Stivala represented ADHD Europe in an online-symposium '**ADHD -The Patient's Perspective**' presenting '**Diagnosis & Treatment of ADHD in Europe, Survey 2020**' that our member organisations contributed to.

We have been attending numerous European online-meetings with stakeholders (policymakers, WHO representatives, national brain councils, neurological patient organisations etc.) to raise more awareness of ADHD and have our voices heard together.

European Federation of Neurological Associations (EFNA)

EFNA offer much value to us with their advocacy workshops, [online training modules](#) and well co-ordinated events with collaborators such as European Brain Council (EBC), European Academy of Neurology (EAN), OneNeurology, FENS (Federation of European Neuroscience Associations) and European Brain Research Area (EBRA)

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.

Gamian Europe

In 2021, ADHD Europe and many of our members have supported and endorsed the MEP Alliance for Mental Health, coordinated by GAMIAN-Europe to continue efforts in campaigning for a European Year for Mental Health during 2022. A [statement](#), has been prepared and sent to the European Commission, signed by over a 100 supporting organisations/individuals and MEPs. This has also been sent to all MEPs to garner EP-wide support, signed by all supporting organisations and MEPs.

Mental Health Europe

ADHD Europe were invited in 2021 to voice our opinion's in various MHE's membership strategy meetings whereby we proposed the following capacity building activities to be involved in during 2022

- Mental Health and Wellbeing in the Workplace
- Effective digital approaches and tools for Mental health
- Mental health-related stigma and discrimination

March 2021

23rd Gamian-Europe '**Campaigning for a designated European Year for Mental Health**'.

April 2021

19th EFNA 'Annual General Meeting'

20th EBC Council's virtual roundtable '**Brain Health in Europe: Fostering Innovation, Improving Outcomes**'. ([report](#))

27th EBC 'Fast-tracking brain innovation in times of COVID-19' **Viljo Wilding represented us by providing the ADHD perspective during Covid** ([video](#))

May 2021

7th – 8th MHE 'Annual General Meeting & Workshop' ([more info](#))

June 2021

9th Gamian-Europe Annual General Meeting

15th Brain, Mind, Pain '**Achieving health equity after the Covid-19 pandemic**' ([report](#))

21st MHE '**Strategic Planning Workshop for 2022-2025**'

24th MHE Network Meeting

29th EFNA, One Neurology '**Global Advocacy Workshop**' ([video](#))

October 2021

12th – 13th EBC '**Brain Innovation Days**' held in Belgium ([report](#))

14th MHE Strategy Capacity Building Workshop

November 2021

3rd EFNA 'Personalised Healthcare - The Future of Neurological Care' introducing the concept of personalised healthcare/precision medicine in neurology. Dr Maria Teresa Ferretti, CSO at Women's Brain Project gave an introductory presentation while leading experts shared their views during the panel discussion. A recording of the event is available to view [here](#).

19th Brain, Mind, Pain (MEP Interest Group) '**Turning principles into action: Best practice in reducing health inequalities**' exploring best practices in reducing health inequalities for those living with neurological disorders and chronic pain conditions and showcased examples of [best practice](#) from the areas of neurology and pain. A recording of the event is available to view [here](#).

**** The ADHD Women Project were invited to present at this Annual Meeting to share best practices!**

December 2021

10th EBC, FENS, EBRA '**The Importance of coordination and collaboration in brain research**' A recording of the event is available to view [here](#).

15th – EFNA 'Annual Partners Meeting'

17th - OneNeurology EU Summit '**Time to make Neurology a Public Health Priority in Europe**' ([video](#))

RESEARCH PROJECT PARTNERSHIPS

TIMESPAN Project www.timespan.eu

On behalf of ADHD Europe Hans van de Velde & Myriam Bea and Andrea Bilbow on behalf of ADDISS participated in several meetings. This project is about: Cardiometabolic diseases (obesity, Diabetes Type2, cardiovascular diseases) & ADHD; and treatment discontinuity in adult ADHD.

CANDY Project (www.candy-project.eu)

The European funded research project CANDY investigates the biological links between these neurodevelopmental disorders and co-occurring somatic illnesses and how treatment and monitoring of affected patients can be improved. The project started on 1st of January 2020 and is coordinated by Radboud University (Medical Centre) in Nijmegen, Netherlands, Hans van de Velde represents ADHD Europe and Andrea Bilbow ADDISS.

The Eat2BeNice Project (<https://newbrainnutrition.com>)

Studying the effects of nutrition and lifestyle on impulsive, compulsive, and externalizing behaviours).

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 it's 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 2021

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