

## ANNUAL REPORT FROM THE BOARD (2020)

### 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 40 members and organisations from 24 European countries.

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. Face to face meetings were not possible due to Covid but virtual ones.

Viljo Wilding is the Tech Lead at ADDISS and was appointed as Technical Advisor to the Board of ADHD Europe, per our statutes, at the 2020 AGM. Since then, his contributions to ADHD Europe have taken up many of his working hours at ADDISS and his responsibilities for ADHD Europe have increased. The Board therefore decided to set up a General Services Agreement for one year with ADDISS for Viljo to act as the Operations Officer for ADHD Europe. He has been providing technical support to the Board and managed the deployment of our new Microsoft 365 platform, which will increase the opportunities for productivity and collaboration. He also built and manages the new ADHD Europe website, acts as systems administrator and database administrator for our mailing list and performs other tasks to assist the day to day operations of ADHD Europe. Viljo acts as the Secretary of the Communications Working Group and, since October, as a member of the Good Governance Committee.

## 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 2020 there were over 20 board meetings held. No meetings were face to face due to covid, however the Board had meetings via zoom or teams. Some of the meetings were just the Executive Committee, but most were 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. The president met with Andrea Bilbow in August 2020 in London for administrative work.

### The Board in 2020

#### **President**

Myriam Bea (Elected June 2020)

#### **Treasurer**

Chantel Fouche (Elected April 2018)

#### **Secretary**

Christina Georgiadou (Elected June 2020)

#### **Vice Presidents**

Marko Ferek (Elected April 2018)

Andrea Bilbow (Elected June 2020)

#### **Ordinary Board Members**

Hans van de Velde (Elected April 2018)

Carola Stivala (Elected April 2018)

Isabel Rubio (Elected April 2018)

Hrannar Björn Arnarsson (Elected June 2020)

You can find out more about our board members at

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

## 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 2020

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

## 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 Committee

**Lead: Myriam Bea**  
**Supported by Viljo Wilding**

Myriam Bea, Andrea Bilbow and Viljo Wilding continue to update our policies. These will be checked annually to ensure they remain current with approval from the Board, and presentation at our Annual General Meetings with our members.

With regards to statutes, ADHD Europe shall be conforming with the new Belgium law for non-profits organisations. Therefore, we shall be looking into our statutes to amend as necessary to be complaint to the new law. Furthermore, we figured out that other changes maybe helpful for the development of our organisation and we want to start a broader discussion about that. The board is in the process of finalizing a draft to be send out in April 2021 and we will call our member organisations to join the newly founded statutes working group. A final draft should be ready by the end of the year and finally discussed and decided at the 2022 AGM.

The Board also have policies for internal Board procedures which help the way we operate as a Board and for running the organization with special focus on volunteers.

We have the following policies currently being newly drafted or redrafted to keep up with identified needs of the organisation:

- Policy Handbook which includes: Volunteer Policy and IT Policy
- Expenses Claim Policy
- Managing Finances, Accounting and Banking Procedures, and Memberships

## Broadcasting ADHD Europe Committee

**Lead: Hans van de Velde**

ADHD Europe is ‘The Voice of ADHD in Europe’. That is why we created the brand “Broadcasting ADHD Europe”. We started maintaining a Youtube channel: <https://www.youtube.com/channel/UC4PNzbOhYIZTPfIXRn4p6fA>

Subjects related to ADHD are popular, like sexuality, relationships, women and hormones, sleep. The number of views on Youtube is growing from about 500 at the start to about 8.000.

During 2020 the following webinars were held:

- 09 May, ADHD and Isolation Helpful hints for families and individuals Kevin Roberts (474 views)
- 01 October Women, ADHD, and Hormones Webinar (7,986 views)
- 19 November, Managing Complex Kids in Complex Times with Elaine Taylor-Klaus (336 views)

For 2021 the following subjects are planned:

- Addiction & ADHD (with Prof Antoni Ramos-Quiroga, psychiatrist, prof at Barcelona university, Spain)
- Survey ADHD in Europe (with our board member Carola Stivala)
- Microbiome (with Dr. Alejandro Arias Vasquez Radboud University, Netherlands)
- Medications, Coaching, Neurodiversity, Treatment & Tools and Relationships.

The webinars are organised by Viljo Wilding as moderator and Hans van de Velde as the host-interviewer. They are happy to be supported by Beatrice Blackett, Nina Hovén, Marko Ferek and Andrea Bilbow.

## Surveys and Research Committee

### Lead: Carola Stivala

Last year during the 2020 AGM, the survey results were presented in a PowerPoint. Together with the workgroup members Dr. Rob Pereira, Stephanie Clark, Joanne Norris, Christina Georgiadou, Andrea Bilbow and Chantel Fouche, the report was written and reviewed. The final report received praise from our Professional Board: “an important document” (Prof. Barbara Franke), “interesting” (Dr. Susan Young).

An ADHD Europe Broadcasting webinar for the ADHD Europe members organisations and the public will be held and a digital copy provided soon to all members. The executive summary of the report “Diagnosis and treatment of ADHD in Europe, Survey 2020” is as follows:

The Survey (answered by 22 member organisations from 19 countries) reflects some positive changes over the last decade, compared to the previous surveys, namely:

- 1) the number of countries with national guidelines for ADHD have increased
- 2) more medication brands are available
- 3) increased specialist awareness of ‘ADHD in adults’ as well as the ‘lifelong condition of ADHD’

Unfortunately, there remain circumstances that are in dire need of improvement:

1) Continued long waiting lists for children to access diagnostic services in most member countries; (contrary to the early intervention advice of the NICE ‘gold’ standard).

2) Continued inadequate provision of health services for adults in many countries (while research shows that untreated ADHD can lead to increased risk self-medication or drug addiction, unemployment, increased traffic accidents, etc) and lack of family clinics where child AND parent can be treated simultaneously (as ADHD is a heritable trait).

3) ‘Generic’ medication brands. Some members report increased medication side-effects for minors using generics, others report positive effects. This urgently warrants unbiased research, including research into comparative medication efficacy and treatment adherence with branded and generic medication. National medicine procurement systems may take mainly price into consideration whilst lacking specialist and patient feedback mechanisms (except for extreme physical side-effects). In addition, ‘out of stock’ situations jeopardise especially youths during examination times.

4) Lack of access to specialists and lack of medication options. National and regional discrepancies exist (especially in rural areas of large countries, island (countries) and Eastern European countries) which are often due to inadequate national funding for mental health services.

5) Continued cultural “stigma” about ADHD amongst specialists, in the media and the general public. Some member countries even mention that dominant professionals apply a psychoanalytic approach only instead of a multi-modal treatment approach for children and adults with ADHD. There are different viewpoints on ADHD as a disorder and on its medication in society.

**The survey shows that -despite positive developments- the ideal situation, in which an individual with ADHD can access the same standard of care and medication wherever they are in the EU, is still very far from reality.**

It is evident that research, support and contact between members of ADHD-Europe is beneficial to the European ADHD community.

Next, the Survey and Research workgroup is interested in a confidential survey regarding the members of ADHD-Europe in order to exchange more current details about their organisation, members, activities and exchange of opinions and most urgent topics of action.

## Social Media & Communications Committee

**Lead: Andrea Bilbow**  
**Supported by Viljo Wilding**

The communications committee with their members Andrea Bilbow, Viljo Wilding, Hrannar Arnasson, Chantel Fouché, Vilhjálmur Hjálmarsson, Christina Georgiadou and Marko Ferek manages ADHD Europe’s digital communications with members and the general public.

### Website

Our new, streamlined website was launched in June 2020. The website showcases our work and partnerships with researchers and other organisations in Europe and across the globe. The website gets around 10,000 unique visitors each month. We invite members to submit content for us to feature on the website – you can email the committee on [communications@adhdeurope.eu](mailto:communications@adhdeurope.eu).

### Twitter

As of March 2021, we have 3,531 followers. We regularly tweet information about our work and about the research projects we are apart of, and we would love to use this platform to promote our members.

## Facebook

We maintain our two Facebook groups and public Facebook page. Our Facebook page has 3,447 followers as of March 2021 – up 1,000 since April 2020! This is thanks to the dedicated work of Hrannar Arnasson, who has been ensuring that the page is active and boosting the Broadcasting ADHD Europe webinars.

Our private Member Organisations' Facebook group has 93 members, and our public Facebook page which anyone can join has 4,103 members from all around the world. This group is moderated by four admins to prevent malicious posts – Andrea Bilbow, Christina Georgiadou, Marko Ferek, and Viljo Wilding.

## Newsletter

We have started to send out an email newsletter, initially on a monthly basis, with a version for members and a version for the general public. This has included information about our research involvements, upcoming webinars, and other interesting information. We have not had much to report in this newsletter in 2021 but we hope to improve the regularity of the newsletter. Our public mailing list has 346 people signed up through our website, and we have 1,245 people on our mailing list for Broadcasting ADHD Europe updates.

## Coaching Committee

**Lead: Hans van de Velde**

**Supported by Carola Stivala & various members**

The Working Group Coaching has met five times since last year's AGM. Group members are: Marie Enback (Sweden), Beverley Nolker and Linda Fox (England), Agnes Hajdu (Hungary), Monica Conversaro (Italy), Beverley Sinton (Belgium), Trish Nymark (Denmark), Sigrún Jónsdóttir (Iceland), Fred Schenk (France), Sue Chrysostomou (Cyprus) and Ute Kögler (Germany). We are happy and proud that a number of members are actively participating in the Working Group Coaching.

Next to medication and other treatments, coaching for people with ADHD is a well known means for support. However not much is clear about what a person with ADHD may expect of a coach. Besides there are not many qualified coaches in Europe that address ADHD.

Aims of the group are: study and exchange information, experiences as well as scientific and practical knowledge about coaching methods for people with ADHD. The group also updates the practical guide from time to time. As a first result we published the *Practical Guide for finding a coach for your ADHD* (June 2020). [Weblink here](#)

This working group will also be advising the board on various issues related to coaching ADHD in Europe. The group is giving input to the webinars group with suggestions for subjects, speakers or other matters within the field of coaching.

One of the plans for 2021 is to actively stimulate the training of coaches and psychologists in Europe to enable them to give professional guidance to people with ADHD. At the moment we are looking for a budget to invest in the acquisition of funding's, like the European Erasmus+ fund. Such a grant could finance courses and trainings for quite a few professionals who already have the basic skills. With the backing or support of ADHD Europe as a legal entity might be able to organise this for the members of ADHD Europe and their professional relations.

## Neurodiversity

**Lead: Myriam Bea**

Group participants are Joanne Norris, Johannes Streif, Marko Ferek, Isabel Rubio and Hans van der Velde. There have been three meetings and a draft paper. We have discussed the definition of neurodiversity and explored ways to integrate the discourse about neurodiversity in our work and in the texts we publish. It needs time to change our own language. We discussed the wordings we and others use. Like, for example instead of “genetic anomaly” use “genetic variant”. Work to be continued and more volunteers welcome.

## ADHD Awareness Month Committee

**Lead: Andrea Bilbow and Chantel Fouché**

At the beginning of 2019, Andrea Bilbow had made contact with the ADHD Awareness coalition based in the USA. ADHD Europe joined with the coalition to roll out a universal theme for ADHD Awareness month across the globe. Meetings started in March 2020 and held regularly thereafter to the lead up of October Awareness Month.

For 2020 the coalition had asked members for input and posted ADHD experts' answers to common questions each day during October. We were delighted with the enthusiastic response from the ADHD professionals who we approached and their willingness to share their expertise. A big thanks to the Common Questions, Reliable Answers contributors. More information about our ADHD Awareness work in October 2020 can be found on the ADHD Awareness Month coalition site <https://adhdawarenessmonth.org/>

For 2021, we hope to continue this theme, tackling more common questions, with reliable answers from professionals around the globe.

## 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

2020 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.

Unfortunately, the 8th World Congress on ADHD was cancelled in 2020, and the 2021 event will take place virtually on 6 – 9 May 2021.

### February 2020

#### **18 February 2020 – Brussels, Belgium – EFNA (Parliament)**

EFNA together with European Brain Council and EAN, brought together at Parliament representatives from WHO, EU Member States, NCD global and European advocacy groups, patient organizations, clinicians and more, along with Members of the European Parliament and European Commission advocating for parliament to include Brain Health as a Global Priority and recognize non-communicable diseases (NCDs). Chantel Fouche represented ADHD Europe at this event.

### May 2020

#### **8 May 2020 - MHE Annual General Meeting & Workshop (Virtually)**

Chantel Fouche represented ADHD Europe at the Mental Health Europe's Annual General Meeting.

#### **25 – 26 May 2020 - EFNA Annual General Meeting & Workshop (Virtually)**

Myriam Bea and Chantel Fouche represented ADHD Europe at the annual General Meeting whereby EFNA had a well informed speaker to speak to us about statutes and the new Belgium Legislation for Non Profit organisations. The workshop covered *Ensuring Meaningful Patient Involvement in EAN activities*.

### July 2020

#### **14 July 2020 – - Gamian Annual General Meeting (Virtually)**

Andrea Bilbow represented ADHD Europe at the annual General Meeting. Four of our member organisations who are also members of Gamian Europe attended this event, represented by Johannes Streif from ADHS Deutschland, Beverley Sinton & Chantel Fouche from ADHD, ASC &LD Belgium, Andrea Bilbow from ADDISS and Christina Georgiadou from ADHD Hellas.

## October 2020

### 17 October 2020 International Consensus on ADHD. Methylphenidate & WHO

Myriam Bea was invited by the Catalanian Federation for ADHD parents to join this conference celebrating ADHD Awareness Month. Participants included Stephen Faroane (President of World Federation of ADHD), Myriam Bea representing ADHD Europe, and three Spanish organisations namely, Maite Urkizu (President of FEAADAH), Juan Pérez (President of FCAFATDAH) and Isabel Rubió (President of Fundacion ADANA) who moderated this online event.

## RESEARCH PROJECT PARTNERSHIPS

### The EU 2020 Strategy

Europe 2020 is a 10-year plan, running from 2010 to 2020 for sustainable, inclusive economic growth. Targets were set for member countries that included reducing poverty, unemployment and increasing educational attainment. The strategy produced a large amount of Grant funding for research and innovation and ADHD Europe has been able to benefit from some of that.

### The CoCa Project ([www.coca-project.eu](http://www.coca-project.eu))

CoCA studies comorbidity between the most frequent psychiatric conditions, ADHD, mood / anxiety and substance use disorders, and a highly prevalent somatic disease, obesity.

Our President, Andrea Bilbow, sits on the Scientific Ethical Advisory Board and the Impact Board of this project and attended regular meetings around Europe.



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

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

The main Goals of Eat2BeNice are:

- to identify nutritional drivers and lifestyle variations that prevent detrimental effects of impulsivity and compulsivity across the lifespan, taking socio-economic environment and sex;
- to characterize the etiological paths leading to impulsivity and compulsivity from the molecular level via the gut (in particular microbiota and their metabolic effects) to the brain;

- to promote societal changes that will counteract maladaptive impulsivity and compulsivity by bringing evidence-based information about health-related behaviours (nutrition, lifestyle) to families, clinicians, the general public, and policy makers

In May 2019 Andrea Bilbow, Mauline Vernon, and Chantel Fouche attended this two day Steering Committee Research meeting held in Brussels on behalf of ADDISS and ADHD Europe, empowering the patient voice into research. It is a great opportunity to catch up with our Professional Advisory Board members, Barbara Franke and Toni Ramos-Quiroga (Head of Department of Psychiatry, Spain). We were also able to chat about work to be done on National Brain Plans, EBRA and more with Executive Director from European Brain Council, Frédéric Destrebecq.

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

Investigating the underlying mechanisms of co-morbidities in neurodevelopmental conditions and epilepsy. In February 2019, our President Andrea Bilbow started working with the CANDY consortium giving input to the grant proposal. The grant application was accepted and approved in September 2019.

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.

## **FUTURE PLANS & TAKING ADHD EUROPE TO THE NEXT LEVEL**

Like last year 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 will be investing incoming resources in the building and maintenance of a new website, a stronger infrastructure, better communication tools, reviewing and maximising our social media presence, promoting and increasing membership and hoping to provide a secretariat to assist with admin, projects and events. We hope to encourage more volunteering and participation from member organisations in different sub groups.

## Member Organisations in 2020

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