



## Annual Report 2015

### The Board presents its annual report and accounts for the year ending 2015

**Our History:** 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. Officially registered in Belgium in 2009, today ADHD-Europe represents 28 organisations from 21 European countries.

Our aim is to advance the rights of, and advocate on every level throughout Europe for, people affected by ADHD and co-occurring conditions in order to help them fulfil their potential.

**ADHD** is a neurological disorder with a 70-80% genetic risk that affects cognitive function and the developmental process, making it more difficult for people with ADHD to manage their lives. Untreated AD/HD also can negatively impact their close kin and family.

**Our Aims:** Across Europe, ADHD is undertreated and poorly accommodated, especially in adults. Our aim is to advance the rights of, and advocate on every level throughout Europe for, people affected by ADHD and co-occurring conditions in order to help them fulfil their potential.

### Review of activities and achievements

#### ADHD –Europe Communication Strategy :

#### Social media

#### Twitter - 1243 followers

Twitter account. [https://twitter.com/ADHD\\_Europe](https://twitter.com/ADHD_Europe) @ADHD\_Europe

At the end of December 2015 we had 1243 followers

#### Facebook

#### **ADHD Europe General group 4000 members**

This group now has 4000 members from across Europe. It is open for the public to read but only members who join can post. The group is moderated regularly by 4 admins to prevent any malicious posting

#### **ADHD Europe Facebook Page 1050 followers**

The [ADHD-Europe Facebook Page](#) carries news from ADHD-Europe ,its member organisations , European organisations. It's content is more political and posts information of interest, details of the work of research collaborations etc. It has been ' liked' by MEPs.

[ADHD-Europe Members](#) group is a members only group for members of ADHD Europe who want to share good practice and ask questions.

Finally, a new, modern and more functional website is still in development.

## **Working in the EU - EU Policy and regulation**

### 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. In 2015, we are half way through the plan. The EU asked citizens and organisations to fill out (a very long!) questionnaire on how well the 2020 strategy was doing, and if anything needed to be changed.

ADHD-Europe argued that social inclusion must take account of the role of neurodevelopmental abilities, like ADHD, in unemployment, educational failure and policy and made some specific recommendations.

Our full response is uploaded to [our private ADHD-Europe members group](#).

## **European Medical Agency (EMA)**

The EMA very much value input from patients and carers when looking at the value of new medications or when re-evaluating old medications. This year ADHD Europe were asked to put forward three parents and/or patients to attend a consultation on a new drug to be licenced in Europe. The group were incredibly impressed by one of the parents we put forward and this resulted unusually in her being asked to return twice more to give evidence and to describe what it was like to raise a child with ADHD. She was also able to talk about the use of medication, its good points and its bad points.

## **EU funded Research Projects on Mental Health**

### **Research Partnerships**

#### **The Aggressotype project**

The Aggressotype Project is a big European Consortium researching aggression with a focus on children , and an emphasis on markers of risk of developing problematic aggression in children with ADHD and/or CD

Whilst persistent aggression can be difficult to treat in adolescence ( especially when the aggression is of the non impulsive, planned, instrumental kind): its been shown that targeting children most at risk of developing persistent aggression for early intervention. can make a real difference both in terms of delinquency rates and better academic outcomes-over time..

Aggressotype is also examining new therapies , both pharmacological and behavioural ,to better personalise treatment Halfway into the project preliminary results for more than a 100 compounds that on theoretical grounds ,were thought might be effective were discussed at the AGM. The compounds are mostly pharmaceuticals, already licensed for use for other conditions , but also include some over the counter foods and supplements.

ADHD-Europe is helping to decide which compounds go on to the next stage of testing. Stephanie Clarke from Aandacht is representing the interests of ADHD Europe and attends meetings for the project. The last meeting was

11-13 November . 3rd AGM Agressotype , Lisbon. European

#### **How you can help :**

any information, anecdotes or studies about patients or parents experiences and preferences , good or bad with medications for aggression that you have ,would help us make better decisions.

## **WP7: Mental health promotion in Schools**

'10-20% of children and adolescents worldwide experience mental disorders, which if untreated, severely influence their development, educational attainment and their potential to live fulfilling lives.

ADHD-Europe is a collaborating partner in the joint action on the 7<sup>th</sup> work package (WP7) on Mental Health in Schools. This is a partnership between the ministries of health of EU states, but also involves local and regional bodies and NGOs. ADHD-Europe is the representing patient organisation on this package.

## **MiND [www.mind-project.eu](http://www.mind-project.eu)**

Attention deficit/hyperactivity disorder (ADHD) and autism spectrum disorders (ASD) are frequent, chronic and highly heritable neurodevelopmental disorders. Despite their societal importance, progress in understanding disease biology has been slow and no curative treatment options are available.

MiND is a pan-European training network MiND (mastering skills in the training Network for attention deficit hyperactivity and autism spectrum Disorders) aims to educate a new generation of researchers in the field of neurodevelopmental disorders, through innovation-oriented research combined with highly interdisciplinary and intersectoral international training. ADHD-Europe is a patient representative in this project and sits on the Ethics committee.

In September 2015 MiND held its two week training seminar for its PhD students. Our President Andrea Bilbow was invited to participate at this seminar and deliver a patient and parent focused talk on raising a child with ADHD and ASD.

## **Participation**

### **World Federation of ADHD 28<sup>th</sup> May 2015 Glasgow**

Our President was invited to give an opening talk at the Conference of the World Federation of ADHD. For the first time this organization recognized the role of patient organizations and through negotiations between our President Andrea Bilbow OBE and Professor Rhode President of the WFADHD. We were subsequently offered five freeplaces at the conference and a free exhibition stand as an acknowledgement.

In her opening address Andrea highlighted the little recognized connection between ADHD and suicide and stressed that one life lost to this disorder is one life too many. Especially when we know that not enough is done soon enough in the lives of young people with ADHD



## Adocare



A project to build a European Expert network in adapted (specialist) Adolescent Mental healthcare.

The first stage of the project investigated the existing state of mental health services for adolescents in Europe. Research included a survey of parents and adolescents. Many ADHD-Europe members participated: A special thanks to Agnes Hadju and Joanne Norris who translated the questionnaire into Hungarian, and German respectively

In April Andrea our President and Joanne Norris travelled to Rome with two teenagers with ADHD. It was a great experience for the young people and gave them a voice about their condition and the treatment and care they receive. In December we were all invited back to Brussels and into the European Parliament where the young people were able to present the findings of the conference in Rome.

29<sup>th</sup> August

Andrea participated in a Patient advisory Group on Suicide prevention in Mental Health

19<sup>th</sup> September

### **Gamian Europe**



The President and Vice President together with Joanne Norris attended the AGM for Gamian Europe. It was with great sadness that we recently learned of the passing of the then president Pedro Montellano, a great man who and great advocate for people with mental health problems

10<sup>th</sup> October

Andrea was an invited guest speaker at the annual Multi Lingual conference in Brussels hosted by ADHD-AS-Dyslexia Family Resource, a member of ADHD Europe. An excellent conference with a host of international experts.



12<sup>th</sup> – 13<sup>th</sup> October

## EFNA European Federation of Neurological Associations



We were invited to attend a two day workshop entitled

### **Advocate for Brain, Mind and Pain -- A capacity building workshop for patient groups**

The focus of the 2015 edition of this workshop was to present delegates with an introduction to EFNA's proposed 'Together Under the Umbrella' communications and awareness campaign, which will be launched in mid-2016. Feedback from delegates contributed to the draft plans and the training provided was to enable those present to get involved in the campaign following its launch in 2016.

We participated in workshops on using social media, capacity building and fundraising.

*Mary Harney, Former Minister for Health* Gave a talk on the Policy makers' perspective when dealing with advocacy groups



This was followed by a visit to the European Parliament where our president gave a talk on the challenges and stigma around raising a child with ADHD

### **Tackling the Stigma of Brain, Mind and Pain Disorders**

*Meeting of the MEP Interest Groups on Brain, Mind and Pain*

*– in partnership with the MEP Interest Group on Mental Health, Wellbeing and Brain Disorders*

## **Membership**

We currently have 23 countries represented in ADHD Europe with 27 member organisations in total.

## **STRUCTURE GOVERNANCE AND MANAGEMENT**

The Board, who are also the charity trustees, are responsible for the overall management and control of ADHD Europe and meet twice a year face to face and communicate inbetween through skype and email.

All Board members give of their time freely and no remuneration or expenses were paid in the year.

## **Risk Management**

The board are responsible for overseeing the risks faced by the charity. This year the president and treasurer reviewed the organisations risk management and will proceed to ensure this is undertaken each year.

Through the risk management processes established for ADHD Europe the executive committee are satisfied that the major risks identified have been adequately mitigated where necessary. It is recognised that systems can only provide reasonable but not absolute assurance that major risks have been adequately managed.

## FUTURE PLANS

The Board intends to continue their current strategies of building a strong organization and membership that has a voice for patients 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 of a new website, strengthening the organisation, promoting and increasing membership and hoping to provide a secretariat to assist with admin, projects and events

The Board requires breadth and depth of experience to carry out its duties effectively and efficiently. When electing board members the important attribute is a passion for the work of ADHD Europe as well as an understanding of personal growth.

Where possible the skills and experience of the Board should comprise the following:

- A member with a financial/accounting background.
- A member with experience of due diligence and good governance
- A member with senior managerial or business experience.
- A member with experience of equal opportunities or disability needs.
- A member with a good understanding of conflict of interest
- At least one female Board member and one male board member.

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### The Board in 2015

President	Mrs Andrea Bilbow OBE elected February 2014
Treasurer	Mrs Christine Getin elected February 2014
Secretary	Mrs Sue Chrysostomou elected February 2014
Vice President	Mrs Stephanie Clark re-elected February 2014 resigned May 2015
Vice president 2	Ms Natasha Michou re-elected February 2014
Board Member	Mrs Christina Georgiadou elected February 2014
Board member	Ms Kate Carr-Fanning re-elected February 2014
Board member	Ms Tessa Reus re-elected February 2014 Resigned October 2015
Board member	Mrs Joanne Norris re-elected February 2014 resigned February 2015
Board Member	Rose Kavannagh elected February 2015
Board Member	Chris McGowan elected February 2015 resigned December 2015

## Our finances

The financial statements show net incoming resources for the year on

Income

membership	3850.00
Donations	
Project Participation	1250.00
sundry	0.15
Income from AGM	7183.42
Total	12283.57

Our expenditure for the year

Website hosting	120.00
Sundry	109.02
AGM Costs	7153.50
Travel	139.50
Banking charges	110.37
Memberships	300.00
Printing	62.28
Total	7994.67