

## New Expert White Paper recommends framework for action to tackle impact of ADHD on individuals, families and society

Brussels, 23<sup>rd</sup> April 2013 – A new Expert White Paper, *ADHD: Making the Invisible Visible*, was today presented to policymakers and key stakeholders by a multidisciplinary group of experts.

This Expert White Paper project was initiated, facilitated and funded by Shire AG and supported by the European Brain Council (EBC) and GAMIAN-Europe (Global Alliance of Mental Illness Advocacy Networks). Medical writing support was provided by APCO Worldwide and Complete Medical Communications, and funded by Shire AG.

The Expert White Paper, based on patient research and independent expert opinion, demonstrates the substantial impact Attention Deficit/Hyperactivity Disorder (ADHD) can have on an individual from childhood into adulthood, in addition to the broader impact on families, welfare systems and national budgets. *ADHD: Making the Invisible Visible* was launched by co-authors Dr Susan Young, Dr Michael Fitzgerald, and Dr Maarten J Postma.

The findings of the Expert White Paper are supported by **MEP, Nessa Childers, co-chair of the European Parliament Interest Group on Mental Health**: "Mental health problems such as ADHD are unfortunately becoming far less of a priority on the political agenda, particularly due to the current economic crisis resulting in widespread cutbacks in resources. ADHD is one of the most neglected and misunderstood psychiatric conditions in Europe. Very few people affected by ADHD receive appropriate diagnosis and support, which leads to a significant impact on quality of life and society. I am pleased that this Expert White Paper lays out sensible and practical recommendations to help ensure better recognition and management of ADHD by all relevant stakeholders working in healthcare, schools, the criminal justice system and the workplace."

ADHD affects 1 in 20 children and adolescents in Europe<sup>1</sup> and, in many cases, persists into adulthood.<sup>2</sup> The Paper highlights that adolescents with a history of childhood ADHD tend to experience greater peer rejection and have fewer close friendships<sup>3</sup> and that children with ADHD are more likely to be bullied than their peers.<sup>4</sup> Academic outcomes are also highlighted as a key impact area for people with ADHD if not managed effectively, and problems at school may evolve into difficulties finding and maintaining stable employment.<sup>5-7</sup>

"This Expert White Paper provides clear evidence that ADHD can have a marked impact on self-esteem, social functioning and academic outcomes," said **Dr Mary Baker, President of the European Brain Council**. "It also shows that timely and effective management can improve quality of life and, with appropriate support, there is potential for people with ADHD to lead fulfilled and successful lives. We want to give everyone with ADHD this opportunity."

The Paper also highlights the broader psychological impact of ADHD, particularly on parents who may also be affected and can experience depression, anxiety and stress.<sup>8,9</sup> ADHD can also have a negative and pervasive impact, with wide-ranging associated costs in terms of healthcare or other services and long-term consequences for multiple aspects of life.<sup>10</sup>

The Expert White Paper sets out five clear, workable recommendations (including specific goals and a list of suggested actions) to help tackle the impact of ADHD on individuals, families and society:

1. Increase informed awareness of ADHD
2. Improve access to early and accurate diagnosis of ADHD, especially via the introduction of early identification and intervention programmes in different policy areas (i.e., education, mental health-related services, criminal justice services and the workplace)
3. Improve access to ADHD treatment and develop a multidisciplinary patient-centred approach to ADHD care and support
4. Involve and support patient organisations
5. Encourage a patient-centred research agenda on ADHD, through more quantitative and qualitative research and through more involvement of allied stakeholders in developing priorities for future research.

"This Expert White Paper not only confirms the impact of ADHD, but most importantly presents solutions to address the societal impact, costs and long-term outcomes for affected individuals," said **Pedro Montellano, President of GAMIAN-Europe**. "These concrete, expert-informed recommendations provide policy makers with a chance to improve the lives of those affected by ADHD and reduce the cost on national welfare systems across Europe. By working together we can make a real difference."

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## NOTES TO EDITORS:

### About the Expert White Paper

'ADHD: Making the Invisible Visible', An Expert White Paper on ADHD: policy solutions to address the societal impact, costs and long-term outcomes, in support of affected individuals.

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The Paper was developed on the basis of a European Expert Roundtable on ADHD, with the participation of clinicians, patient advocacy groups and representatives from the education and criminal justice systems. The Roundtable addressed specific issues and challenges around the management of ADHD and provided a forum for the discussion of policy recommendations. The three co-authors, Dr Susan Young, Professor Michael Fitzgerald and Professor Maarten J Postma, formulated the outcomes of the Roundtable into the White Paper, which reflects their views based on their clinical and scientific experiences.

### About The European Brain Council (EBC; [www.europeanbraincouncil.org](http://www.europeanbraincouncil.org))

The EBC is a coordinating council formed by European organisations in neurology, neurosurgery, psychiatry, basic brain research (neuroscience), as well as patient organisations and industry. It represents a vast network of patients, doctors and scientists, and these stakeholders along with its industrial partners make it suited to work in close partnership with the EU Commission, the European Parliament and the World Health Organization (WHO), as well as other decision-making bodies. The EBC was officially founded on 22 March 2002 in Brussels, and has offices in Brussels and Florence.

### About GAMIAN-Europe (Global Alliance of Mental Illness Advocacy Networks; [www.gamian.eu](http://www.gamian.eu)).

GAMIAN-Europe was established in 1998 as a representative coalition of patient organisations. Putting the patient at the centre of all issues of the EU healthcare debate, the organisation aims to bring together and support the development and policy influencing capacity of local, regional and national organisations active in the field of mental health. GAMIAN-Europe currently brings together some 50 organisations (local, regional and national) from 20 European countries.

### About Shire AG

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