



# Youth Mental Health in the Community: the role of patient's organisations

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# GAMIAN-Europe



A patient-driven pan-European organisation, which represents the interests of persons affected by mental illness and provides:



# Advocacy



1. Act as the voice for patients both at EU and national level, and demonstrate that this voice is useful as well as indispensable
2. Ensure that patients are at the centre of all aspects of healthcare provision
3. Work to improve the availability, accessibility, and quality of treatment for all mental health problems

# MEP's Interest Group at EP



At least three times a year GAMIAN-Europe organises meetings at the EP with Members of the European Parliament.

## The meetings started on 28<sup>th</sup> April 2010:

- 26<sup>th</sup> October 2010 - Health inequalities and mental health
- 9<sup>th</sup> February 2011 - Mental health in 'Europe2020 Mental health in the Active and Healthy Ageing Innovation Partnership (AHAIP)'
- 3<sup>rd</sup> May 2011 - Stigma and Depression
- 22<sup>nd</sup> September 2011 - Mental Health and the Brain
- 24<sup>th</sup> January 2012 - Depression
- 24<sup>th</sup> April 2012 - **Mental health for Children and Adolescents (ADHD)**



# Information and education



1. Provide reliable and quality information on mental health problems to patients and general public
2. Improving the training, education and understanding of mental illness for patients, carers, health professionals

# Information resources



## Convention 13

### Lisbon, Portugal, 2010

Theme: "Strengthening of Patient's voice in the Improvement of Mental Health Care"

Amazonia Lisboa Hotel	Delegates	57
Lisbon	Organisations	29
October 21- 24, 2010	Countries	22

[Read here the report written by William Ashdown](#)  
[Photo report](#)

This Convention has been made possible by the following companies:

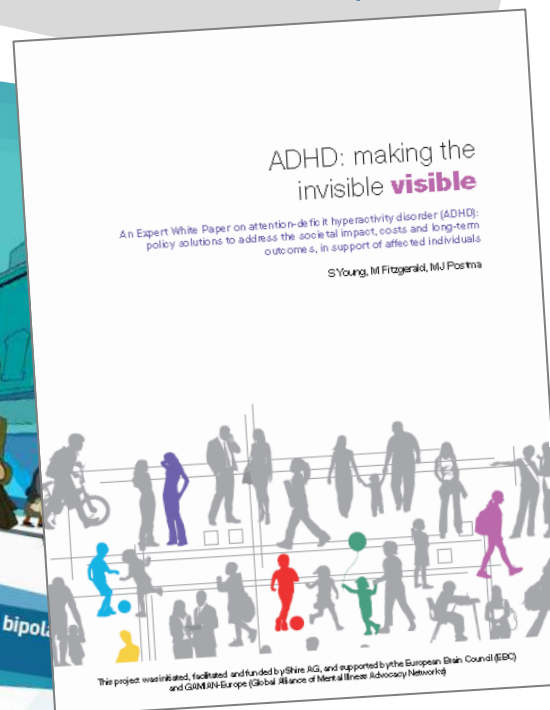
- GlaxoSmithKline plc
- Pfizer Incorporated
- H. Lundbeck A/S
- Eli Lilly and Company

Grant providers had no control over the content of the convention

newsletter,  
handbooks on  
specific mental  
illnesses, website  
and Facebook page.



information and support to  
member organisations by means  
of educational seminars and  
conventions



# Stigma and discrimination



1. Increase awareness, knowledge and understanding of mental health problems
2. Help reduce stigma, prejudice, and ignorance in relation to mental health problems and fight discrimination
3. Patient's rights - Focus on the development and enforcement of rights for persons affected by mental health problems, e.g. access to appropriate treatment



# Partnerships and cooperation



with other stakeholders with a view to:

- supporting the development of mental health policies which take account of the views of patients
- acknowledgement of role of patient organisations as partners in decision-making and facilitators in the sharing of best international practice
- securing the best possible treatment for patients with a mental illness and at the earliest possible opportunity

# Partnership/Cooperation (examples)



- ✓ Involvement of GAMIAN-Europe:
  - WHO-Europe (Mental Health Action Plan)
  - Joint Action on Mental Health and Well Being
  - EC Group Mental Health Experts
  - EUFAMI
  - European Brain Council (EBC)
  - Expert Platform focus on Depression
  - European Patients Forum (EPF)
  - EPPOSI
  - European Medicines Agency (EMA)
  - EPA, ECNP, UEMS
  - others...

# Best practice award for members



Shares experience and examples of good practice to strengthen the role and voice of patient organisations and effective input in EU and national policy development.



**Greek association KINAPSI was the first winner of the GAMIAN-Europe award to member organisation**

Facilitates an open and inclusive pan-European dialogue among patient organisations and other interested bodies to exchange information and ideas.

# PERSONALITY AWARD



**Dr. Lawrence Gonzi,  
Prime Minister of Malta  
(2005)**



**Mr John Bowis, Member  
of the European  
Parliament (2006)**



**Professor Norman  
Sartorius, Professor  
of Psychiatry (2007)**



**Mr Kjell Magne  
Bondevik, Norwegian  
Prime Minister (2008)**



**Mr. Stephen John  
Fry, Actor, Writer,  
Director (2009)**



**Mr. Jürgen Schefflein,  
Policy Officer DG  
Sanco (2010)**



**Mrs & Mr Vappu and Ilkka  
Taipale, Finland (2011)**



**Dr. Barbara Lopes  
Cardozo (2012)**



**Dr. Matt Muijen –  
WHO Europe  
(2013)**



# Research Projects (FP7)



## MOODFOOD

Impact of food and nutritional behaviour, lifestyle and the socio-economic environment on depression

### Dissemination

- Newsletter
- Website
- Facebook
- Events

### Patient Advisory Board

MA

Mar

adv

MIN

E-C

rese

the (cost-) effectiveness of internet-based treatment for depression in comparison with standard care.

# Surveys



Stigma 2006, 2010

Physical and Mental health, 2011

Adherence to treatment, 2012

Mental health and Workplace, 2013



# Patients organisations



What can they do on behalf of mental health in youth ?



# Advocacy/Policy



- ✓ Awareness campaigns highlighting the importance of mental health in youth: extensive use of the **media** (but with criteria). Patient led campaigns are more effective

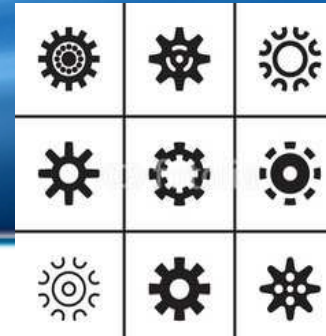


# Advocacy/Policy



- ✓ Raise awareness on politicians at European and National level to the benefits of addressing mental health in youth: burden + **costs of not treatment** (not reaching full potential).

# Advocacy/Policy



Isolated cogwheels

- ✓ Cooperation with other stakeholders involved, to increase the discussion on mental health in youth, in order to establish an **articulation** that allows concrete outcomes in the solving of specific problems associated to these ages.

articulation



Articulated and functional outcome

# In the fight against mental disorders...



*Clinicians and Patients  
are not in opposite sides*

But...

They surely are in  
different positions within  
the same side



# Care/Treatment



Different perspectives



Different approaches

Different results



Different Methodologies





# Those differences are...



## a tremendous opportunity!!!



# Care/Treatment



✓ Patients organisations are a necessary complement to professional services;

✓ have a very different **environment**. They are “Affective Shelters”.

✓ have a very **diferent approach** towards the illness (holistic).

To combat physical/neurological/biological symptoms is very important

**but**

Psychotherapy/psycho-education/self-help groups are complementary, and very important too.

✓ have a focus on **recovery**.

# Care/Treatment



- ✓ can represent an alternative view on mental illness, based on members' personal experience.
- ✓ highlight that the daily life experience of patients is diverse.
- ✓ demonstrate that dialogue between peers can be very helpful;

# Care/Treatment



- ✓ Different strategies to improve resilience and cope with the social impacts of having a mental illness – STIGMA
  - ✓ Psychoeducation (patients/families)
  - ✓ Peer support (experts by experience, legitimacy. e.g. self stigma)
  - ✓ Self help
  - ✓ Recovery
  
- ✓ help young people at risk of developing mental health problems, namely on tackling the that often prevents young people seeking help.



# Care/Treatment



- ✓ can assist young people on how to best access and use the Mental health services from the patients' perspective.
  - ✓ This is important because the difficulties in transitions between child and adult services, due to the poor coordination and the lack of age appropriate mental health services/doctors to support this particular group.
- ✓ early intervention in community settings

# Care/Treatment



- ✓ can educate their members in self management of their disorder
- ✓ can inform/educate their members in risk assessment and decision making.
- ✓ provide access to reliable information. Information is not knowledge.

# Care/Treatment



- ✓ Promotion of healthy lifestyles and preventing other health and social concerns for young people related to a poor mental health:

- educational achievements
- relationships
- substance use
- employment

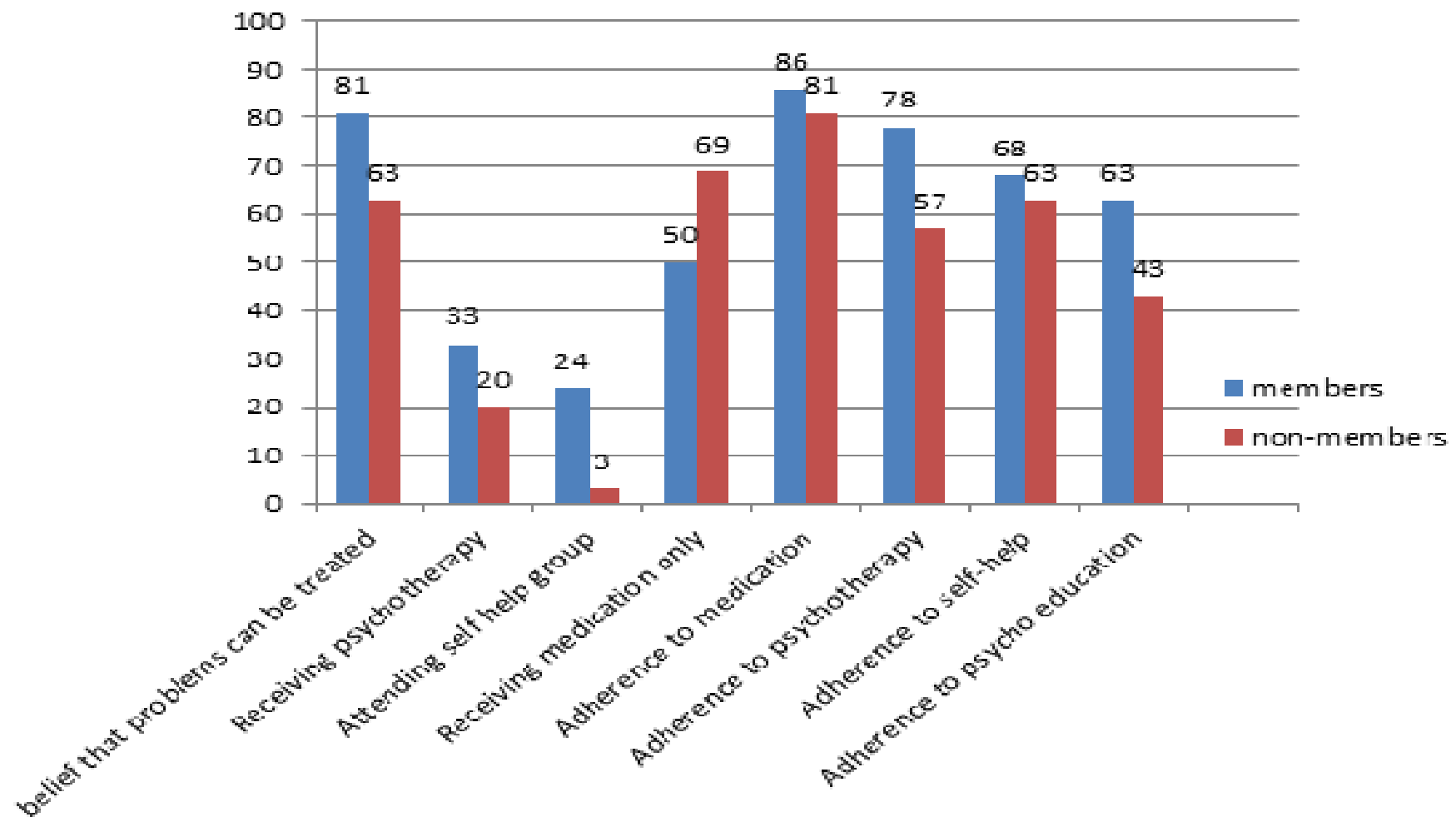
- ✓ Good practices

# Care/Treatment



- ✓ Access to research results and new developed treatment (geographically, financially, etc...);
- ✓ Participation in research projects

# Members of patient associations tend to have more positive attitudes towards treatment





# Volunteer Work



- ✓ Should be coordinated by professionals
- ✓ Empowering for the volunteers, patients or not.
- ✓ Increase awareness on mental health issues as well as literacy
- ✓ Very efficient in terms of cost
- ✓ Can contribute to get additional funding in the community
- ✓ Can bring new perspectives to the organization
- ✓ Increase the capacity of the organisation

# THANK YOU



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