

MENTAL HEALTH  
KEEP TALKING ABOUT IT

# Newsletter GAMIAN-Europe

October 2015

ISSUE 2015 - 3

## In Memoriam

### Pedro Montellano

Dear reader,

It was shocking news on 2<sup>nd</sup> of October to hear that our President and friend Pedro had passed away. It was a very sad moments to all of us.

Our President, a young and promising leader, living with a happy family - Filomena and their children- a good friend, suddenly left us. Only two weeks earlier, I spent three days together with him in Brussels.

How can we imagine GAMIAN-Europe without Pedro? He was very fond of the organisation and was happy and honoured to be our President - one of his dreams.

Pedro was not only a patient but he was our patient Number One and we were proud to have a patient as our president. He was GAMIAN-Europe's ultimate representative of patients and families that are affected by a mental illness and he did our organisation proud. Pedro was highly engaged and he tried to do his utmost in representing GAMIAN-Europe at numerous events on mental health issues. He had a good reputation with other European advocacy leaders. This sudden loss of Pedro, a few weeks ago, still gives my wife Debbie and myself difficult moments.



Every moment that we spent during the past 12 years will be remembered forever. Pedro, with his charming smile and big hug, was an authentic man with a huge, human and open heart for everyone. I lost a good friend and all of us are still shocked, but the good memories of our Pedro will remain a comfort to us.

GAMIAN-Europe will do all , not to forget Pedro. We will treasure his legacy and continue to do all we can, in favour of the patients.

I loved Pedro very much, I will miss him.

*Let him rest in peace.*

Yoram Coheni (Vice President)

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## In Memoriam

### Pedro Montellano

As you probably know, Pedro Montellano, President of GAMIAN-Europe, passed way on Friday 2nd October, now already more than three weeks ago.

Pedro's passing away was sudden and a shock to all who knew him.

Pedro has been a champion for people who experience mental health problems for many years, both in his home country Portugal and at a European level, having himself a bipolar disorder.

Pedro was the President of GAMIAN-Europe. for the past three years. Many of you may have had the opportunity to meet with him in one of the different and many roles he held at a European level.

Pedro was committed to improve the understanding of mental illness and to improve the life of all those who experience this, in whatever form.

To this end, Pedro worked incessantly, driven by his belief that more needed to be done to ensure that people experiencing mental illness live a fulfilling life.

Pedro was not only the President of GAMIAN-Europe. Those who knew him considered him as a great colleague and friend.

Pedro will be remembered as a very warm, committed person always there to support, share his wisdom and a laugh.

Pedro will be greatly missed but he will stay in the memory of all who had the honour and pleasure to know him.

Our sincere and deep condolences go to his wife Filomena, his three children and his parents.

*May he rest in peace.*

Dolores Gauci (past President)



## GAMIAN-Europe's ANNUAL GENERAL ASSEMBLY

*Brussels, 19 September 2015*

On Saturday, September 19<sup>th</sup>, GAMIAN-Europe held its General Assembly in Brussels.



It was the first time a General Assembly was held separately from a conference. ADDISS UK was officially welcomed as a new member. ADHD-Europe was present as a new member as well. Its President, Andrea Bilbow, stated that the organisation works towards recognition of ADHD as a mental health issue.

After a warm welcome by John Bowis, as Master of Ceremony, our President Pedro Montellano provided an overview of past and planned activities of GAMIAN-Europe.



***"We are all GAMIAN and need to make it stronger."***

Pedro Montellano underlined the importance to hold the General Assembly in Brussels, a European environment where some 60% of the European laws about advocacy and mental health are being developed. He emphasised the need for representation at a European level to have a strong voice as representation at the national level only is not sufficient. Therefore, he suggested that we should all bring GAMIAN into our national-level meetings, quoting President John F. Kennedy: "Ask not what your country can do for you, but what you can do for your country".

He reminded participants that GAMIAN-Europe is not just its Board; it is all of us. We have to be more engaged and find out and how we can individually contribute how we can put GAMIAN-Europe in our daily lives.



***The European Personality Award 2014/15*** was attributed to Professor John Copeland, former President of World Federation of Mental Health.



### **Convention & regional seminar in 2016**

According to the corrected minutes of the convention 2014 in Budapest, we should plan a Regional Seminar every year and a Convention every two years, if funding allows.

The last regional seminar was held in Serres-Greece and so the next will be held in 2016. Daniel Cernik from KOLUMBUS (Czech Republic) expressed the interest of his association to host the event in Prague on 18 -20 March 2016.

For the 2016 Convention, it was decided that organisations from Turkey, Ireland, Portugal and UK should submit proposals for hosting this event.

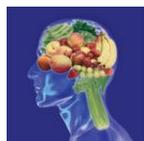


### **Website & Newsletters**

The new GAMIAN-Europe website is more dynamic and members have also found their way to the social media, using Facebook more and more to post news on mental health issues and events.

Publication of the quarterly newsletter of GAMIAN-Europe is working out well.

The dissemination activities of the EC research projects, Mood Food, Master Mind and E-Compared, are a little behind schedule due to limited reporting from the project partners. Now that the projects have come to speed and the right communication channels with GAMIAN-Europe have been established, newsletters will be issued more regularly in the future.



### **Financial issues**

The financial report 2014/2015 was presented by Rebecca Muller (Treasurer). GAMIAN-Europe's finances have been approved by the auditor. Positive results stem from industry, research and consultancies (i.e. patient members are delivering advice as experts). Thanks to the income stemming from research projects, GAMIAN-Europe is less dependent on industry.



GAMIAN-Europe has lost one corporate member (Roche).

The financial report was approved unanimously, and so was the discharge of the Board.

It was pointed out that GAMIAN-Europe is an European NGO based in Brussels and staff are paid on a self-employed basis. The budget was unanimously approved.

The auditor is retiring and the General Assembly will select a successor. John Bowis asked to pass the decision on new auditors, to the Board.

### **Awakening Foundation, Hungary**

Robert Kristof (Awakenings Foundation, Hungary) spoke about the many problems that the Awakening Foundation is currently facing as a result of the migrant crisis. First, the organisation's financial power has been decreased by 20%. As Hungary is a

Schengen country, it has to register the many migrants (50,000 + over the last year) who arrive there. A critical situation at the borders exists as a result for men, women and children, especially for children who are alone because they have lost their parents. They need food, baby care products, blankets, etc. Emotional and mental health support for migrants, volunteers and policemen is needed. The government policy and response has been very disappointing. For example, the messages to the migrants are written in Hungarian.

There is a pronounced upsurge of NGOs and citizens who want to help, often coordinated by a Flash Mobs.

### **Miscellaneous**

GAMIAN-Europe has helped EBC/CINP raise awareness on the issue of accelerated CNS (*Central Nervous System*) drug discovery for improved patient care. Innovative partnerships are starting to be established in this field.

GAMIAN-Europe is on the Advisory Board of the 'Mental Health Index', a study carried out by the Economist Intelligence Unit. It is difficult to explain brain development. GAMIAN-Europe is working with EBC on this issue.

GAMIAN-Europe works with EUFAMI on a joint project entitled 'Inventory on Access to Treatment for Expert Platform on Depression'.

GAMIAN-Europe is represented on the EPF (*European Patient Forum*) Board and can address important issues in relation to mental health and comorbidities.

Awareness should be raised about GAMIAN-Europe's involvement with the current refugee crisis, as the mental health needs of refugees and asylum seekers should not be forgotten. A statement calling on all countries, the Commission and the European Parliament to take account of these needs should be prepared (was prepared and sent to the media two days after the General Assembly).

Pfizer has contacted GAMIAN-Europe with regard to having a Board representative from GAMIAN-Europe on a new project relating to the impact of mental health on sexual health.

### **Closing & Dinner**

After closing the General Assembly, John Bowis invited the participants to a well-deserved aperitif and dinner.



## Upcoming events

### Vlaamse hersteldagen

Vlaamse Vereniging Geestelijke Gezondheid (V.V.G.G.)

Ghent (B)

17 - 18 November 2016

More info, click [here](#)

### Regional Advocacy Seminar Nordic Countries

EPF (European Patient's forum)

Lund (Sweden)

24-25 November 2015

Details, click [here](#)

### European conference on disability-inclusive development cooperation

EDF (European disability forum)

Brussels (B)

3 December 2015

For more information and to register, click [here](#)

### "Supporting Young Disabled People to Explore Sexuality and Relationships as Integral to their Social Inclusion and Independent Living".

Council of Europe Youth Centre

Strasbourg

17 - 24 April 2016

Application, click [here](#)

## Call for participation

### Project RADAR

IMI (Innovative Medicines Initiative)

2015 . . .

GAMIAN-Europe is involved in a research project on remote monitoring. Part of the research is to identify and provide examples of how remote monitoring (by smartphone and watches) can benefit patients in terms of identifying relapse signs or other information that might support their choice of treatment. There are three diagnostic groups involved – MS, epilepsy and depression - and a number of issues will be discussed with the patient groups who are supporting this bid.

**We hope that GAMIAN-Europe members can be involved in:**

1. Identifying clinically important outcomes that would benefit from remote data collection
2. Building a visual format for the data so it is understandable by all (including clinicians)
3. Determining privacy and confidentiality that is acceptable to patients
4. Involvement in determining the regulation of these devices

The project aims to have representatives from diagnostic specific pan-European and national groups to sit on the steering group and to help with some of the clinical studies.

These groups cannot be partners; however, the project hopes to find resources to support their involvement.

**If you are interested to cooperate, please, as soon as possible/before 30/11/2015**

**mail to:** [assistant@gamian.eu](mailto:assistant@gamian.eu)

## EU News

by Christine Marking  
(GAMIAN-Europe EU Liaison)



### 'Access to health services in the European Union' pays special attention to mental health

The Expert Panel on Effective Ways of Investing in Health (EXPH), which advises the European Commission on health policy development, has launched a public consultation on the Panel's Opinion on the 'Access to health services in the European Union'. This Opinion addresses barriers to accessing health care and explores policy measures that can overcome them. Ways to improve equity could include matching health needs and financial resources, affordable and accessible health services, the availability of a sufficient number of health workers with the right skills, well-equipped facilities within easy reach, the availability of quality medicines and medical devices and services that are relevant and cost-effective. It also pays special attention to access to health services for underserved groups such as Roma, undocumented migrants and people with mental health problems.

The Opinion pays special attention to access to healthcare of people affected by mental health problems, and echoes many of GAMIAN-Europe's advocacy priorities, e.g. the need to

- Address the gap between need and utilisation of mental health care services;
- Improve access for the treatment of common and severe mental disorders, and the delivery of early intervention, prevention and mental health promotion;
- Recognize that people with mental disorders are at greater risk for poorer physical health and have higher levels of disability and earlier mortality and that people with severe mental disorders and comorbid physical health problems are less likely to receive standard level of health care;
- Recognize that people who experience social exclusion and marginalisation are more likely than the rest of the population to experience mental health problems;
- Integrate and co-ordinate services across the health and social care sectors as well as good coordination between primary health care and mental health services;
- Increase knowledge related to access and health literacy for people with mental health problems (as well as other

vulnerable and underserved groups), taking into account levels of education and literacy as well as linguistic background.

GAMIAN-Europe has prepared a detailed response to the opinion which is available on our website.

[More information:](#)

### Joint meeting of the Interest Group on Mental health and the Brain Mind and Pain Group



On 14 October, the Interest Group on Mental health and the Brain Mind and Pain Group met to address stigma in relation to brain and pain disorders and

mental health issues. Background to the meeting was the growing need for more awareness and clear information and stigma, as well as the need to listen to those who suffer stigma and how it impacts on their lives.

The first part of the session was devoted to testimonials by patients and relatives of patients; these were followed by presentations on the evidence of stigma, i.e. overviews of the EFNA and GAMIAN -Europe surveys on the patient experience of stigma. One of the findings of the EFNA survey was that 57% of participants feels stigmatised at least occasionally. In relation to workplace, it was found that 11% of the total sample (457 persons) perceive a relevant workplace stigma. The findings showed that 16% of the total sample (712 persons) perceive a relevant social stigma. And in terms of overall well-being, 17% of the total sample (710 persons) perceive an overall negative well-being. Another interesting finding was that persons who think that their condition should have been diagnosed earlier perceive a significant higher workplace and social stigma and a worse overall well-being compared to persons who think that their condition was diagnosed on time.

The GAMIAN-Europe survey was carried out in 2006 as well as in 2011, in order to see if there were (positive or negative) changes. The surveys were designed to measure the levels of internalised stigma, the degree of perceived discrimination and the levels of self-esteem and empowerment).

It was found that a positive evolution on self-stigma and empowerment had taken place. However, there was a small increase in the level of perceived hold negative attitudes by the general public.

Stigma has been a major item in other GAMIAN-Europe surveys as well. For instance, the 2011 survey on Physical aspects of Mental Health showed that 20% of the patients that experienced barriers to contact a doctor to treat physical problems indicated stigma and fear of disclosing their mental health problem to their GP as the reason. The 2013 survey on Mental



Health and Workplace (2013) revealed that 50% of the patients did not want to inform their employers on their mental health problems.

For the full report: see [GAMIAN-Europe website](#)

### European Parliament strengthens mental health in EU Health and Safety in the Workplace

On 6 June, the European Commission adopted an EU Strategic Framework on Health and Safety at Work 2014-2020. This takes into account the results of its evaluation and contributions from a wide range of stakeholders, including worker's and employer's representatives. The European Parliament is in the process of deliberating this report, and when going through the Parliament's Employment Committee, GAMIAN-Europe worked with MEPs to insert a number of amendments to ensure sufficient attention for mental health in the workplace. Many of these were adopted in Committee, and the report will now be voted by the parliament as a whole at its November plenary session. [For more information:](#)

### Interview with John Bowis Member of GAMIAN-Europe's Board

John Bowis works as International Health Policy Adviser since 2009; before this date, he was a MEP (Member European Parliament) for a period of 10 years. He is expert at chairing meetings, a good manager of committees and works for the improvement of people's lives in UK and Europe. He also brings his experience in this area to GAMIAN-Europe.



Below some answers to the questions that we asked during our interview.

#### **When/how did your career in the area of "mental health care" start ?**

I was involved with mental health issues, first as an Education Chairman in a London Borough and then as a member of a Community Health Council in the area of Inner London for which I subsequently became the Member of Parliament.

When John Major became Prime Minister he invited me to become Minister for Health and Social Services – a responsibility that convinced me that the two services should work more closely together. Within my Ministerial portfolio was mental health and learning disability. We had a target of reducing suicide among people with mental health problems, which we met and a programme of enabling many more people to be treated and cared for in the community rather than in remote institutions.

My experience in government gave me a life-long wish to improve our mental health services and to prevent, wherever possible, mental illness and disorders. So, when in 1997 we lost the election and my seat, I was pleased to take up a request from the World Health Organisation to support their two global

campaigns – Nations for Mental Health and Out of the Shadows (the latter on epilepsy). While working on these I became involved with the Finnish plans to develop mental health promotion for their 1999 EU Presidency. By 1999 I was elected to the European Parliament and was nominated by the Parliament to work with the Finnish plan.

#### **When/how did GAMIAN-Europe come into the picture ?**

Thereafter I used every opportunity to put mental health on the EU agenda and eventually we persuaded the Commission to come forward with its Mental Health Green Paper and then plans to improve every area of mental health by seeking and disseminating good practice.

Among the many people from outside parliament and commission I brought in to give evidence at hearings and discussion meetings were a number of patients/users and this is when I worked closely with GAMIAN-Europe and grew to value their input immensely. They helped me to realise that the experience of a patient of his or her condition and of the treatment and side effects is a fundamental expertise to be ranked alongside the expertise of the practitioner and the scientist.

#### **Until now, you have been the only member from UK. Any idea why UK MH-organisations are not interested in GAMIAN-Europe ?**

I was very pleased to be invited to join the Board of GAMIAN-Europe. Its President when I first knew them was British but in recent years GAMIAN-Europe had been without British representation – largely I think because the leading mental health organisations in the UK did not have a majority of patients/users on their Boards and were therefore ineligible for our organisation. I am glad to see that a UK organisation was at last present at our recent convention.

#### **What message do you, as a member of GAMIAN-Europe's Board, have for the member organisations and readers of this newsletter?**

GAMIAN's Board contains excellent representatives of the mental health experience and each is an ambassador for our organisation when they perform on international stages. Pedro Montellano, like Dolores Gauchi before him, has been a much loved and effective voice of GAMIAN-Europe and we shall miss him enormously but our consolation can be that he presided

over a team, all of whom are ready to run with the baton he has handed on. That will be the best honour we can do his memory.

## FOCUS ON MEMBER'S ACTIVITIES

### WMH Day in Hungary

Robert M Kristof  
Awakenings Foundation

An afternoon party was organised together with Rehab Critical Mass - an organisation for the disabled -to celebrate World Mental Health Day. The programme consisted of a video clip contest on mental health, a psycho-drama workshop, a slam poetry session, a memorial session dedicated to J. NASH, glass painting, a stress management workshop and an 'Ask the psychiatrist' session. A popular Hungarian dish was served to all people (approx 70) who joined the event.

An afternoon-evening event which is hard to forget!

### "Treating Psychosis with Dignity", Greece

13th October 2015,  
Spyros Zorbas

This event was organized by KINAPSI, the Movement for the Siblings of People with Mental Health Problems ([www.kinapsi.gr](http://www.kinapsi.gr)), and took place in the Antonis Tritsis Amphitheatre of the Organization for Culture, Sport and Youth, of the Municipality of Athens. Extensive reference was made to World Mental Health Day 2015, the theme of which was Dignity in Mental Health. Participants heard about current issues and the problems faced by the much troubled Mental Health Sector in Greece.

### Ups&Downs Annual Conference, Special edition , Belgium

10th October 2015,  
Erik Van der Eycken

Ups & Downs celebrated its 20<sup>th</sup> anniversary during the forum in Ghent. After a warm welcome by Rebecca Müller (President), three psychiatrists gave presentations on the topic of bipolar disorder and mental health care. Two experts by experience shared their experience during treatments, with the audience of 180 people. The Ups and Downs Award was attributed to these two speakers. The event was closed with a drink. This conference was a success whereas many attendees expressed their appreciation to the organisers.

## GAMIAN- Europe's News Flash



\* **ROAMER project** Help us to increase mental health research! [More info](#)  
Associação de Apoio aos Doentes Depressivos e Bipolares

Click [here](#)

\* **Schizophrenia Awareness Week 2015**, [short movie](#)

\* **What Treated Illness Like Illness?** If People Physical Mental

Click [here](#)

