



**MENTAL HEALTH**  
KEEP TALKING ABOUT IT

# Newsletter GAMIAN-Europe

Apr-May-June 2018

ISSUE 2018- 2

Dear reader,

21st March has already gone by, some weeks now. Spring has arrived and nature has awakened from hibernating. For most of the persons affected by mental health issues, sunshine supports more positive moods. The days are getting longer and this makes life a bit more enjoyable. GAMIAN-Europe also feels invigorated, and as you will see, many new and positive initiatives have been started. This newsletter reports on those and will continue to do so throughout the year.

As always, we welcome your comments and contributions. Launching a new project? Organised a useful meeting or event? Made contact with other stakeholders? Do let us know and we will be happy to spread the word.

Enjoy reading this newsletter!

*Editorial Committee.*

*Christine & Erik*



**Foreword by Hilikka Kärkkäinen**  
(President)

Dear reader,

Welcome to this issue of our newsletter, which highlights our work during the first three months of this year.

First of all, GAMIAN-Europe has gone through the process of renewing its website and logo, making it more accessible as well as visually attractive. We have succeeded to launch this new look in April 2018.

*We have gone through the process of renewing our website*

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In February, GAMIAN-Europe published a report entitled 'Sexual Health Impact on Mental Well-Being', which you can find at our website. Many thanks to all those that contributed to this important piece of research.

Also in February, I was invited to present the patient's perspective on shared decision-making in the treatment of depression', on the occasion of Servier's SAPHIR project's meeting in Paris. This event was attended by psychiatrists from all over the world. It is encouraging to note that the patients' voice is heard more and more in the practice of mental health care and that new



methods are taught to health care professionals, taking better account of the voice of patients.

In March, GAMIAN-Europe presented its work at the annual EPA Congress and exhibition in Nice. Many delegates visited our stand and many new contacts were made. I was also invited to present the patients' point of view in a session addressing the measurement of quality outcomes of person-centred mental health care at the EPA Forum. In addition, I presented the patients' perspective on the ways in which psychiatry can contribute to the promotion of human rights of people with mental health problems in the ECPC panel. After the EPA Congress and AGM, GAMIAN-Europe received an invitation to join the EPA Board. This ex-officio Board seat is a great honour to us and it will help intensify the collaboration between our two organisations.

I have also been very pleased work on the Board of the European Patients' Forum as it enables us to be

directly involved with the organisation's many worthwhile projects. An example: EPF is running a campaign – 'Patients + Participation = Our Vote for a Healthier Europe' -with the aim to put patients' issues at the heart of next year's European elections. GAMIAN-Europe will be actively supporting this.

Also in March, GAMIAN-Europe organised a closed expert workshop in the European Parliament, entitled 'Improving Patient Empowerment and Self-Management of Care in Mental Health'. This workshop led into to the preparation of a comprehensive Call to Action on this topic, which we plan to present in a meeting of the European Parliament Interest Group on Mental Health, Well-being and Brain Disorders planned for May.

We have been continuing our work on three ongoing Research Projects and preparing several new projects as a partner.

*Wide recognition among all EU level stakeholders that the patients' voice is crucial in developing mental health care.*

Last but not least, we are currently finalising our workplan for the next two years, which will be available on our website soon. We are looking forward to the coming period in a positive way, despite the challenges we face in securing funding for our activities. Ironically, there seems to be wide recognition among all EU level stakeholders that the patients' voice is crucial in developing mental health care; yet, it seems difficult to find sustainable funding to do our work. Finding resources to carry out our valuable work takes up much of our current resources. Let's hope this changes in the coming months.

*Hilkka Kärkkäinen*

*President*

## Call for membership renewal

Dear GAMIAN-Europe Member,

Thank you for your continued support and contribution to GAMIAN-Europe and its activities. The organisation continues to advocate patients' rights and their needs. With a view to achieving the objectives and deliver the projects that have been approved within our membership and the Board, we very much look forward to your contribution this year.

As you know, GAMIAN-Europe is mainly funded through the contributions from its members and partners; therefore, we are grateful for your continuous support.

As we are at the start of a new year, we would like to remind you to kindly pay your membership fees for 2018 as soon as possible. It is important for us to collect the membership fees in the first quarter of 2018 between January and April to help the organisation plan better and enable us to implement the workplan. Alike past years, the fee amounts € 150.

Please let us know if you require an invoice for accounting purposes.

**ING Bank, Marnixlaan 24, 1000 Brussels, Belgium**

**IBAN CODE BE 59 3900 4438 4326**

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Advantages of full membership include:

- ✓ Information on and involvement in all GAMIAN-Europe activities;
- ✓ Newsletter (4 x year) and newsflashes on the GAMIAN-Europe Twitter and Facebook accounts;
- ✓ Voting right in the General Assembly;
- ✓ Invitation to the bi-annual Convention (2 nights' free accommodation and reimbursement of travel expenses up to 350 €);
- ✓ Possibility to participate in regional seminars (for full members of the region concerned);
- ✓ Active involvement in GAMIAN-Europe (research) projects and surveys;
- ✓ Eligibility for the GAMIAN-Europe Pedro Montellano Good Practices Award.

If there are any changes in your contact data please let us know by sending an email to [secretariat@gamian.eu](mailto:secretariat@gamian.eu) or [executive.director@gamian.eu](mailto:executive.director@gamian.eu)

## Breaking the silence: Sexual health impact on mental well-being

As you may recall, the impact of mental health on sexual well-being was explored by means of a GAMIAN-Europe survey last year. The first results of the survey were already presented at the WPA congress, held in Berlin in October 2017.

In the meantime, the analyses of the outcome of this survey have been done and a full report is now available. This report provides an overview of the descriptive statistics (frequencies, percentages) about the respondents' background characteristics, mental health, treatment and sexual health.

Some crosstab analyses have been performed in order to analyse the relationships between the background characteristics and sexual health on the one hand and mental health / treatment and sexual health on the other side.

for the full report click [here](#).

### Conclusions of the study report

- About 76% of the respondents believe that their mental health condition impacts their sexual health; at least people perceive that mental health influences sexual health.
- There were three main categories of respondents: bipolar disorder (29%), schizophrenia (19%) and depression (17%), with some 20% of the respondents reporting 'other', often referring to multiple diagnoses. People living with bipolar disorder report less impact on their sexual health as compared to the other respondents. They also more often discuss changes in their sexual behaviour with professionals.
- Respondents taking medication most often did not discuss changes in their sexual behavior with anyone after starting mental health treatment whereas people involved with psychotherapy or counselling most often talk with professionals about these changes. Furthermore, almost 4 out of 5 respondents never asked their doctor to change medication because of side effects affecting their sexual health.
- Only 51% of the respondents is satisfied with their sexual life whereas 70% feels free in expressing their sexuality. Many respondents (34%) - mostly female and non-

heterosexual - experienced a traumatic sexual experience or sexual abuse in the past.

- Most respondents feel comfortable talking about sexual health. Most of them talk about sexuality issues with their doctor. Yet, 13% do not discuss these issues with anyone.

## EU News

by Christine Marking  
(GAMIAN-Europe EU Liaison)



### Advocacy on patient empowerment and self-management of care

Empowering people affected by mental health conditions has been and is one of GAMIAN-Europe's main concerns. The reasons for this are obvious:

The burden and prevalence of mental health conditions is huge: 11 % of the European population experience mental disorders every year. These conditions go hand in hand with substantial stigma, costs and consequences that impact individuals, families and carers, health and social systems, society and the economy. As a consequence, there is an obvious need to address mental health conditions in the most effective way. Empowered patients, managing their own care and treatment, can support this need in many ways.

However, while the notion of and need for patient empowerment has been increasingly accepted when it comes to patients affected by physical health conditions – mainly because of a powerful advocacy activities of patient organisations such as the European Patient Forum - this is not the case for those affected by mental health problems; many individuals and organisations have highlighted the disempowering attitudes and behaviours towards people with mental illness which exist in society.

*When it comes to mental health, the competence of patients to self-manage their treatment and care is usually viewed as doubtful.*

In addition, many people with physical health problems already self-manage their care and treatment and are seen as competent and capable to do so. However, when it comes to mental health, the competence of patients to self-manage their treatment and care is usually viewed as doubtful.

This is why GAMIAN-Europe convened an expert workshop on 7 March. This closed meeting, held in the European

Parliament hosted by MEPs Tomas Zdechovsky, Francesc Gambus and Cristian Busoi, was the first and most crucial step in the development of a Call to Action on patient empowerment and self-management of treatment and care, which will be presented in the European Parliament on 16 May.

It aimed to

- explore the current situation in relation to patient empowerment and the ability to self-manage treatment;
- identify the barriers to empowerment and self-management of treatment;
- come forward with recommendations to improve the situation.

The meeting, chaired by GAMIAN-Europe Board member John Bowis, was attended by representatives of a variety of organisations active in the field of mental health, who all provided their thoughts and insights, feeding into a Call to Action.

The Call is now being elaborated and will highlight what can be done to empower patients and to engage them as partners in care. It underlines that patients should be seen as resource in this respect; and empowering patients will ensure the best possible 'use' of that resource, while putting patients at the heart of care provision.

Once ready, GAMIAN-Europe aims to obtain the endorsement of key stakeholders and MEPs; the Call will then function as the organisation's main advocacy tool in relation to empowerment.

### Third (and final) meeting of the Mental Health Compass Forum

The third EU-Compass for Action on Mental Health and Well-being Mental Health Forum was held in Luxembourg on 8-9 February, with a focus on community-based mental health services and developing integrated approaches to governance - often referred to as 'mental health in all policies'. GAMIAN-Europe participated in this event, in which a major EU Compass scientific paper on Community Care was presented. The meeting, attended by some 150 representatives from across the EU, consisted of plenary and breakout sessions, addressing key topics such as the results of the annual EU Compass surveys regarding the activities of Member States and stakeholders.

All presentations and scientific papers can be found by clicking [here](#).

The Compass has now come to an end; mental health will now be addressed as part of the European Commission's general programme on chronic disease.

GAMIAN-Europe continues to advocate for a specific EU-level Action Plan on Mental Health and has developed a

comprehensive outline of what such a Plan might entail. This can be found on the GAMIAN-Europe website.

### Stakeholder consultation on the future EU research programme

Earlier this year the European Commission invited stakeholders across the EU to express their views on what the next EU-level R&D programme should be focusing on. GAMIAN-Europe was pleased to have the opportunity to share its views. In our response, we underlined the need for the future programme to specifically address mental health, taking account of the recommendations of the ROAMER project.

*Meaningful involvement of patient organisations and better dissemination of research findings*

This project, funded by the EU, developed a comprehensive blueprint for EU level mental health research and it would make sense for the EU to implement its findings. In addition, we called for a more meaningful involvement of patient organisations and better dissemination of research findings.

Our response was very much in line with that of other leading mental health stakeholders, as the Dutch Trimbos Institute (one of the Mental Health Compass Consortium partners) took the initiative to develop close cooperation between stakeholders on this topic. We would like to take this occasion to warmly thank Trimbos for this action as well as for the pleasant cooperation.

### 'Anoiksis', Patient Association, The Netherlands Member of GAMIAN-Europe

By Aadt Klijn, Bill George, Leo Finn

Anoiksis is an independent association for, and run by, people who are susceptible to psychosis (Psychosis Susceptibility Syndrome, PSS).



This condition was formerly called schizophrenia or schizo-affective disorder. The association was founded in 1993 with the intention of providing a counterweight to the, then prevalent, restrictive psychiatric regime imposed upon patients with a PSS diagnosis.

The name Anoiksis was taken from the Greek metaphor for "open mind", in the sense that people with the PSS

diagnosis are mostly unable to use natural filters that prevent over-stimulation of the mind, which can lead to psychosis. This assertion is, even now, still applicable, as some patients speak of being over-burdened by events in their everyday lives. It was therefore a forward-looking concept at the time.

Anoiksis' core business is to provide contact with fellow-patients. The country is geographically divided into 25 regions, with each region headed up by a coordinator. The coordinator arranges meetings where fellow-patients can gather together socially to compare experiences or share a meal or listen to a presentation on interesting developments. This level of contact is supported by a quarterly magazine *Open Geest* (Open Mind), and a website [www.Anoiksis.nl](http://www.Anoiksis.nl). At national level, the association is administered by an elected Board that operates from an office in the University Medical Centre, Utrecht. The work of the association, with the exception of one part-time office worker and one invited lay-member, is done by patient volunteers. We are therefore able to state that Anoiksis is an (almost unique in the field) authentic association for, and by, patients. That this formula works can be seen by our growth in membership, from 100 at the foundation to nearly 1000 at present.

As a secondary but integral task Anoiksis campaigns against stigma. The name Anoiksis itself was the first contender for an alternative name to replace schizophrenia and schizo-affective disorder. It was actually Anoiksis' first anti-stigma campaign; but it did not get very far. We then searched for an alternative name from

amongst our own members, who came up with *Psychosegevoeligheid* (Psychosis Susceptibility)

*The name Anoiksis was taken from the Greek metaphor for 'open mind'*

A number of initiatives followed, including articles in highly-regarded professional journals, a poster campaign, and finally a booklet, *Psychosegevoelig...?* (Psychosis susceptible...?), which helped the term PSS to become acceptable. This booklet contains the actual experiences of some of our members, each with an accompanying professional commentary. The booklet, by being authentic, serves to educate the public, the professionals and other patients in an open and honest way about our "condition".

To promote this campaign outside The Netherlands, and to keep abreast of developments beyond our borders, Anoiksis established a "*Landelijke Werkgroep Buitenland*" (national working group foreign countries), since renamed "Anoiksis International", which was in fact the original name given to it by our founder Maarten Vermeulen. This group, which operates as a separate Anoiksis region, also attends important events and has had the Dutch booklet translated into English, "Psychosis?... Me?". The booklet, in English and in Dutch, can be downloaded from the website [www.psychosegevoelig.nl](http://www.psychosegevoelig.nl).

The long trail to reduce stigma continues. Together with other anti-stigma initiatives such as GAMIAN-Europe, we will continue our efforts.

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