

EUFAMI celebrates 30 years

of supporting Families Affected by Mental Ill Health

News Letter

Vol. I, NOVEMBER 2022

Dear Friends,

EUFAMI is pleased to announce the publication of the 1st edition of its new trimonthly newsletter.

This year EUFAMI celebrates 30 years of service in supporting families affected by mental ill health, and with a newly formed Board and the appointment of a new Executive Director, the organisation has entered an era of reformation and redevelopment.

From the development of our new *Strategic Plan 2022-2024* and the implementation of our revised *PROSPECT Programmes*, to carrying out advocacy *training workshops* and actively participating in several *European projects*, conferences and round-tables, EUFAMI continues to be committed to building closer networks and to collaborating substantially with its member organisations

and European institutions, as well as to encouraging and supporting the establishment of new family associations, while upholding and safeguarding the human rights of families and carers.

Last but not least, we are delighted to inform you that we are in the process of constructing a brand-new, user friendly and engaging website, which will come to you at the beginning of 2023.

Sincerely,
Urs Würsch
EUFAMI President





News



ECNP Congress - Vienna, Austria

EUFAMI participated at the European College of NeuroPsychopharmacology (ECNP) Congress.

Read more here.

JA ImpleMENTAL

EUFAMI participated at the kick-off meeting of JA ImpleMENTAL in Rotterdam, Netherlands. This is an EU joint project on Good Practices in Mental Health Service delivery and suicide prevention.

Watch out for more information in our next issue of EUFAMI's Newsletter.





MEP Alliance for Mental Health

EUFAMI joined the hybrid meeting of the MEP Alliance for Mental Health on 25 October 2022, organised by MEP and GAMIAN-Europe, where MEPs and stakeholders issued a strong call for an ambitious, cross-sectoral and inclusive mental health strategy.

Read more here.

About Us



WHO WE ARE

EUFAMI was founded in 1992 after a congress, which took place in 1990 in De Haan, Belgium, where carers from all over Europe shared their experiences of helplessness and frustration when living with severe mental illness. They resolved to work together to help both themselves and the people they cared for.

EUFAMI is a democratic organisation, registered in Belgium as an international non-profit organisation. We have an ongoing commitment to improving care and welfare for people affected by mental illness. We also enable our member organisations to act jointly at a European Level, combining their efforts and sharing experience.

See our statutes here.

OUR MISSION

EUFAMI's mission is to represent all family members of persons affected by severe mental ill health at European level so that their rights and interests are recognised and protected.

OUR VISION

EUFAMI's vision is that every person affected by mental ill health and their family members receives the understanding and support they need to participate in their community as they choose, and share in the social, economic and political rights of that community, without exclusion or discrimination.

Read more here.



Strategy 2022-2024

INVOLVING FAMILIES AND CARERS

Since its founding in 1992, EUFAMI has dedicated itself to supporting and advocating on behalf of family members and carers in mental health across Europe. We continue to support the rights of involved families and carers to be part of the process of service delivery. We believe family members have a significant role to play in the recovery of people with mental illness.

Over the thirty years of our existence, EUFAMI has witnessed many positive changes in the quantity and quality of mental health services across Europe. We are proud to have played our part in this progress.

There is more to be done, however, including the delivery of family and carer support and training by mental health services, the continued reduction of stigma as it affects family members and the strengthening of the family voice in many countries.

EUFAMI's new Strategic Plan builds on previous documents and renews our commitment to more focused activities in support of national member organisations and to espouse the need for advocacy and research, which is aimed specifically on the issues that affect families as carers of persons with mental illness.

If you wish to view EUFAMI's full new Strategic Plan, please click here.

ADVOCACY

EUFAMI will advocate, at European level, for families and carers affected by mental ill health, regardless of social, economic or ethnic differences.

MEMBERSHIP

EUFAMI will connect and support EUFAMI Membership by encouraging and supporting the establishment of new family associations and strengthening those already in existence.

RESEARCH

EUFAMI will ensure the active participation of families and carers in research by supporting and promoting family-focused research and also by sharing research outcomes with member organisations, the media and the wider public.



Annual Report 2021

30 YEARS OF SUPPORTING FAMILIES AFFECTED BY MENTAL ILLNESS

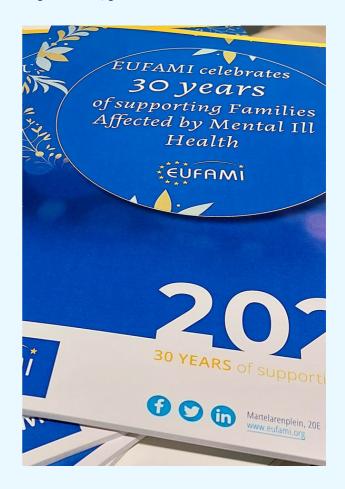
EUFAMI's Annual Report for 2021 was released in June 2021 and features activities and projects the organisation had been involved in during that year, alongside the important work presented by its member organisations. This is also the first time EUFAMI's new Strategic Plan 2022-2024 is introduced to its members.

An extensive section is dedicated to EUFAMI's flagship Programme, PROSPECT. The PROSPECT Programme was first implemented just over 20 years ago and is committed to improving the well-being and quality of life of informal carers of people with mental ill health.

During the past couple of years EUFAMI experienced a number of internal changes, amongst Directors at Board level and also staff changes. Three Senior members reached the end of their service and three newly elected Directors were welcomed on board.

A new Executive Director also took over in March 2021 as well as a new Communications and Administration Officer.

If you wish to download EUFAMI's Annual Report 2021, please click <u>here</u>.



Prospect Plus



EUFAMI'S PROSPECT TRAINING PROGRAMMES

An innovative European training initiative, which opens up fresh perspectives for individuals with direct experience of mental health conditions, whether they be people with lived experience, family and friend caregivers, or health and social care professionals.

In 2001 EUFAMI member associations recognised the need for empowering family and friend caregivers. Something new was needed instead of information-based courses. A new approach to training was developed via the Prospect project and 3 Training Programmes, and a Common Ground Module were designed and produced.

The training focuses on establishing a space in which together the participants can co-create, co-produce, share and think about important aspects that concern them as individuals with direct experience of mental health conditions, whether they be people with lived experience, family and friend caregivers, or health and social care professionals, and aims to support the recovery process.

The training is based on innovative concepts such as:

- peer to peer
- multi-stakeholder team approach
- personal experience and participation (not information dispensing and receiving)
- not providing answers or solutions but opening up to new ways of thinking and perspectives

20 years on, The Prospect Training Programmes are still considered a valuable experience and are implemented by various EUFAMI member organisations in the Czech Republic, Finland, France, Slovenia, Spain and Sweden.

The training programmes have just undergone a process of updating and the new Prospect versions are now ready for testing!

The first national test training session will take place in Finland this November and December. Other countries will soon follow. Thanks to our collaborating partner Johnson & Johnson, there is the opportunity to cover the costs of these test training sessions, with the objective to to improve access and benefits for all EUFAMI member organisations.

If you are interested in finding out more about participating and implementing Prospect, please click <u>here</u> or email Gwen Crawford at <u>projects@eufami.org</u>





INVOLVE

FAMILY FRIENDLY MENTAL HEALTH SERVICES

The INVOLVE Project is a project developed by EUFAMI and it was first presented to member organisations in June 2022, during EUFAMI's General Meeting. The project commenced in April 2022 and will be concluded in December 2023. There are currently five countries actively participating in this project: Slovenia, Malta, Hungary, Greece and Ireland.

The project is an advocacy training programme, where participants train to appropriately and effectively advocate for family members, friends and other care partners to be involved and for their voice to be heard during the recovery of the person they care for.

Promoting partnership in recovery

Current practice in most mental health care systems means that many relatives, friends, partners and carers feel excluded from having or giving an informed view of their expectations and experiences in relation to the social needs and treatment of the family member they are supporting.

Mental Health Services often unconsciously and consciously exclude family members, friends or other care partners, from the care and treatment process and focus only on the person presenting a mental illness.

International research reflects this experience and is supported by EUFAMI's most recent research on the Value of Caring.

Context

This project is based on the following points, which are central to the successful delivery of Mental Health Services:

- The project acknowledges that, in some circumstances, the involvement of the family may not be appropriate as not all persons have involved families.
- The consent of the individual service user is required for family members to be involved.
- The concept of patient confidentiality is always respected therefore consent to share information is needed.
- Where such consent cannot be given, services can and should always listen to the opinion and experience of family members.
- Mental health care professionals should, as part of all pre and post graduate training, receive input on the importance of family care in the context of modern mental health care services.



EUFAMI Position Paper on Coercive Practice in Mental Health Services

Coercive practice, such as involuntary admission and coercive measures, such as seclusion, restraints and forced medication, are used in mental health services in all European countries. Compulsory treatment in the community is used in some countries. The rates of involuntary hospitalisations in Europe differ between countries[1].

Grounds for compulsory admission often include an identified need for treatment to which people are unable or unwilling to consent, and which cannot safely and effectively be delivered in the community.

Concerns are often expressed that some people may be at risk of self-harm, or harm to others, if coercive measures are not enforced.

Although regulated by national law, involuntary admission and coercive measures conflict with treatment based on informed consent, shared decision-making and recovery-focused care.

EUFAMI believes that coercive practice, even when used as a necessary last resort based on national law, is essentially the failure of mental health services to respond with non-coercive alternatives.

In order to minimize coercive practice in mental health, training should be mandatory on topics of de-escalation skills, human rights, medical ethics, mental health legislation, alternatives to involuntary admission and use of coercive measure as well as on recovery culture.

Coercive practice should only occur as a last resort in circumstances when no less restrictive alternative will respond adequately to the risk of physical harm to the person themselves or others.

[1] Marie Chieze1, Samia Hurst2, Stefan Kaiser1 and Othman Sentissi1, "Effects of Seclusion and Restraint in Adult Psychiatry: A Systematic Review"

If you wish to view the full paper on EUFAMI's position on Coercive Practices in Mental Health Services, please click <u>here</u>.



EUFAMI Board Member & Member Organisation Meeting 15-16 October 2022 Vienna, Austria

EUFAMI's first in-person Board Members' and Member Organisations' meeting, since the COVID-19 outbreak, took place in Vienna, Austria on 15-16 October 2022.

EUFAMI had the opportunity to present its new strategic plan 2022-2024, "Involving Families & Carers" and discuss further on the organisation's operations and action for the next coming months. A detailed account was also given to EUFAMI's past, current and future projects.

The meeting was carried out at the HPE Headquarters in Vienna, Austria having the Danube River as a backdrop, and was successfully completed with the support of our generous hosts at HPE.

Representatives of the below Member Organisations attended the meeting:

HPE from Austria
Similes VI. from Belgium
Bedre Psykiatri from Denmark
Rethink from England
UNAFAM from France
EPIONI from Greece
LOKA from Hungary
SHINE from Ireland
ARIADNE from Italy
FamiliarMente from Portugal
Salud Mental España from Spain
Schizofreniförbundet from Sweden
VASK from Switzerland
ADFERIAD RECOVERY from Wales



Members from 14 countries had the opportunity to discuss the involvement of families in Mental Health Care Services, as well as:

- what the main issues have been in Mental Health Care Services in their country over the last three years
- what the main activities of each organisation have been and
- if there are any exciting or new activities each organisation would like to share with other EUFAMI members.



Other Projects



The SUCESS Project commenced in February 2022 and will be concluded in February 2024, having the NGOs EPIONI and Similes Brussels at the wheel and supported by partners from Belgium, Greece and Croatia.

EUFAMI acts as an associated partner in this project, which aims to share good practices and training programmes towards support of family members of people with ill mental health in Europe.

Watch out for more information in the next issue of EUFAMI's Newsletter.





EUFAMI participates in the Breaking Depression campaign, which launched in September 2022.

Read more here.

Running in the FAMILY – Understanding and predicting the inter-generational transmission of mental illness. The kick-off meeting of this project will take place in Rotterdam, The Netherlands on 2-4 November 2022.

EUFAMI will be there!

Watch out for more information in the next issue of EUFAMI's Newsletter.





EUFAMI is an assosciated partner of he Art4Me Project, which commenced in March 2020 and will be concluded in June 2023, having the Danish Committee for Health Education at the wheel and supported by partners from Belgium, Italy, Portugal, Croatia and Greece.

The project shares practices of art and art therapy for adults with ill mental health.

Read more here.

EUFAMI acted as a partner in this project, and shared Good Practices for the psychoeducation of Children of Parents with mental ill health in Europe.

The project commenced in December 2019 and was concluded in January 2022.

Read more here.





Membership News

EPIONI Greece

3rd Caregivers and Depression Event

EPIONI organised for the 3rd year the event "Caregivers and Depression". The event took place on October 7, 2022 at the Amarilia Hotel in Vouliagmeni, Athens Greece and was broadcasted online.

"Caregivers and Depression" hosted psychiatrist Mr Dimitrios Kontis, who presented the topic "Caring for caregivers with depression", psychiatrist Mr Dimitrios Roukas, who referred to the epidemiological data of depression in Greece, and psychiatrist Mr Dimos Dimelis, who spoke about suicide in depression.

Dr Kelly Panagiotopoulou referred to the hidden depression of the caregiver, and the director of the European federation Eurocares, Mr Stecy Yghemonos, made a presentation on the topic "European Care Strategy and Informal Caregivers".



The conference was under the auspices of the Office of the European Parliament in Greece, the Region of Attica, the Municipality of Vari – Voula – Vouliagmeni and the Hellenic Psychiatric Association and is held in association with mental health organisations from Greece.

Sponsors: VIANEX, Janssen, and Pfizer Communication sponsors:

https://dailypharmanews.gr/,
www.psychologynow.gr
www.iatronet.gr,
Caregivers&Depression_programme

HPE Austria

From October 14th - 16th 2022 EUFAMI'S board meeting plus a Member Organisations' meeting took place in the Headquarters of HPE Austria, Vienna. After such a long time of "distancing" and virtual meetings, it was wonderful to see and, in some cases, meet the delegates from several countries. The different presentations were all of great interest and, above all, the exchange of views and information was extremely enlightening.

HPE Austria was very honoured to host this meeting & we look forward to closer cooperation, especially with our neighbouring member states, in the future.

Bedre Psykiatri Denmark

At the moment, there are general elections to the national parliament in Denmark and for Bedre Psykiatri, the mission is to contribute to the political agenda (media-wise, academically and politically), so that we keep a continuously focus on strengthening the effort for people with mental illness and place emphasis on recognizing and supporting caregivers in their role in the lives of people with mental illness.

After the election, Better Psychiatry will also be keeping a strong focus on government commitment to ensuring an appropriate, effective and long-lasting mental health sector.

It is Better Psykiatri's assessment that the recent political agreement provides an opportunity to start solving psychiatry's major challenges. But in the longer term, more money and more binding arrangements are needed for all ten years of the plan. It is now Bedre Psykiatri's future task to contribute to the process, so that the 10 year action plan becomes a reality and as successful as possible.

Confederacion Salud Mental Spain

In October 2022, MENTAL HEALTH SPAIN has launched a campaign to empower young people to defend their mental health.

This campaign, financed by the Ministry of Social Rights and the 2030 Agenda, is part of the different actions scheduled for the month of October by the Confederation, under the slogan 'Please Like mental health, for the right to grow in wellness'.

Swedish Schizophrenia Association Sweden

StigmaWatch

StigmaWatch works for accurate reports on mental illness in the Swedish media. The project started in 2019, and is funded by "Allmäna Arvsfonden". The project team has had the help of 68 StigmaWatchers from all over the country.

Up to October 2022 the project has processed approximately 1000 reports from StigmaWatchers. For StigmaWatch's great work, the project has received third prize from Fokus Patient 2021 as "Patient Representative of the Year". The group has, in addition to the handling of all the stigma cases, among other things written articles, participated in training, meetings, produced informative movies (schizophrenia, stigma etc), interviewed people with experience of schizophrenia and created a wide network.

For information: www.stigmawatch.se



With the hashtag #DaleLikeALaSaludMental, MENTAL HEALTH SPAIN has disseminated different infographics with messages that seek on the one hand, to deactivate certain ways of thinking or acting in a moment of emotional discomfort, and, on the other, to make young people and adolescents aware that their problems and feelings have the same validity and importance as those of adults, and that expressing them without fear helps to take care of mental health.



Besides this campaign, MENTAL HEALTH SPAIN held the 5th of October a commemorative event for World Mental Health Day, chaired by Her Majesty the Queen and the 25th of October the Confederation organized the conference 'Please Like mental health. Let's talk without filters', in which young people have shared their experiences with mental health, their concerns and their proposals in this area.



Rethink Mental Illness - England

UK charity Rethink Mental Illness launches new campaign: 'Turn the tide the tide on mental health.'

In the UK, we are facing a cost-of-living crisis, with household bills soaring. At the same time, our national health and social care systems are in crisis and struggling to meet demand.

Our mental health and financial problems are inextricably linked. So for people living with severe mental illness, it can feel like wave after wave of bad news. While the problems we face are big, they are solvable with the right level of commitment from government.

That's why Rethink Mental Illness has recently launched a new campaign calling on the UK government to 'Turn the Tide on Mental Health' by:

- Publishing a fully funded 10-year plan on mental health and well-being which includes necessary action for all government departments.
- Committing to support the poorest households through the social security system, by raising financial support in-line with inflation.
- Providing funding for the National Health Service (NHS) and social care system to meet increasing need.

For those of you in the UK, we'd greatly appreciate it if you could write to your Member of Parliament and share our campaign action on social media: www.rethink.org/turnthetide



SHINE - Ireland

Shine Annual Report 2021

Shine officially launched our Annual Report 2021 at a recent Information and Networking Event in Dublin. The report highlights the key achievements of the organisation, including the delivery of 1,554 one-to-one individual recovery support sessions, 7,500 information and support sessions and a reach of 20,623 people directly through our work in local communities, despite the COVID-19 pandemic and ongoing economic challenges.

Early Intervention in Psychosis Survey

Findings from a national survey carried out by Shine, in partnership with Mental Health Reform and the HSE National Clinical Programme for Early Intervention in Psychosis, aimed at gathering information from people with lived experience of psychosis and their family members and supporters, highlighted areas for improvement in the provision of dedicated specialised support services for those living with psychosis. You can read more about the survey findings here.



See Change Green Ribbon Campaign

Shine's national stigma reduction programme See Change celebrated 10 years of the annual national Green Ribbon campaign across the month of September, hosting two campaign launches in Cork and Dublin and a wide range of awareness raising events throughout the month. You can read more here.

Headline Mental Health Media Awards 2022

The Headline Mental Health Media Awards recognise excellence in media coverage of mental health issues, celebrating those whose work brings to light challenging stories of mental ill health. With 9 categories, the Awards highlight work from all media platforms across local and national media in Ireland Shortlisted nominees announced on 11th November with the Awards ceremony taking place on 7th Dublin. (Headline is a December in programme of Shine)



Adferiad Recovery Wales

This Summer, Adferiad Recovery launched the 'Only Human' campaign, which focused on ways to tackle addiction-related stigma in Wales. We held 27 event days across Wales in order to raise awareness about the harmful consequences of addiction-related stigma, and to encourage people to question their beliefs about addiction and those who experience it.

As part of the campaign we developed the 'Only Human' survey, informed by a panel of experts with lived experience of addiction. The survey sought to provide insight into people's lived experience of addiction-related stigma and to gather suggestions on how best to overcome stigma and support people struggling with addiction.

Some key findings from our survey were;

- Half of our respondents had experience of addiction, and alcohol was most commonly reported
- Addictions were typically co-occurring, with many respondents reporting having multiple addictions at the same time
- 80% of respondents with addiction had experienced related stigma, and nearly 70% of these respondents felt this prevented them from seeking support
- Almost 96% of respondents were in favour of treating addiction in the same way as other health conditions and respondents proposed a number of potential ways to combat addiction-related stigma in the future

To read the Only Human report in full, click <u>here</u>. For the brief summary version, click <u>here</u>.





FamiliarMente - Portugal

On the 29th November 2022 we had our VII National Congress, which was held in partnership with the National Coordination of Mental Health Policies. We had the presence and participation of regional leaders of mental health and the National Coordinator, recently appointed, under the new diploma that defines the functioning rules of the SM Services within the scope of the SNS. We've had also the President of EUFAMI in person and the Executive Director in a remote intervention.

Participation in the work group for the revision of the Mental Health Law, which was finalized, and the draft law was approved at the Plenary Session of the Assembly of the Republic recently on behalf of family members. We also had our first meeting of the Commission for Monitoring the Management of the Availability of Medicines, of which FamiliarMente, in the person of our President of the Board Joaquina Castelão, is part, by indication of the President of Infarmed (the National Authority for Medicines and Health Products, its mission is to regulate and supervise the sectors of medicines for human use and health products), representing the families of people with mental illness.

In request of the National Coordination and in articulation with the Coordination of the Central Region, FamiliarMente will participate in training actions aimed at newly hired professionals for the Local Mental Health Teams and encourage the creation of family associations in the region.

Ozma - Families Promoting Mental Health in Israel

Our purpose is to affect policies concerning people and families affected by mental health. Our latest contribution is the successful initiative to the inclusion of a section to the Law of Welfare Services for People with Disabilities (July 2022), that ensures the rights of people with mental health issues to receive all the services entitled by this law. The law was laid in front of the Israeli Parliament, by the Ministry of Welfare, that up to now excluded from its services people with physical and cognitive disabilities if they had, in addition, mental disability. The inserted section ensures that from now on people with multiple disabilities, one of them mental disability, can no longer be excluded from receiving services provided by the Ministry of Welfare.

Ozma participated, as officer of the court, in a petition to the Supreme Court claiming that under the Law of Rehabilitation of People with Mental Disabilities (2000), the services of which are provided by the Ministry of Health, should include assistance with rent fees to people entitled to the services of supported community living. The sum ruled by the court will be added to the support for rent provided by the Ministry of Housing.



MHA - Malta

Walk for Mental Health Awareness Empathy, Empowerment, Education

The Mental Health Association organised a walk in support of the World Health Organisation theme for 2022; "Make Mental Health and Well-being for all a global priority". This theme is especially relevant to Malta, and this walk was set to raise awareness about mental health issues, demand the availability and accessibility of high quality, human rights based services in a holistic manner including the medical, social and economic sector. We also highlighted the need to prioritisation and more investment is given to mental health.

To policy makers and all those who have a responsibility to DELIVER and WORDS ARE TURNED INTO CONCRETE ACTION.



MHA took the opportunity to show its gratitude to the family carers who play a crucial role in the care of their loved ones, they need to be recognised, valued and supported in their needs even financially, to all service providers in the mental health sector who are not always appreciated and valued for their work. They need adequate resources to enable them to respond to the full medical, psychological and social needs of the service users and their families. To voluntary groups and NGO who have many committed and talented individuals working tirelessly however we need more of them.





EUFAMI
Martelarenplein 20E
Leuven 3000
Belgium











