



Annual report 2018



IF YOU HAVE A MENTAL ILLNESS IT'S OKAY TO ASK FOR HELP

TUKEA. TOIVOA. MUKANA.



A sustainable approach to depression:
moving from words to actions



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INTRODUCTION

On behalf of my fellow Board Directors at EUFAMI I am pleased to present our report on EUFAMI's activities and achievements in 2018. As you will see, throughout the year progress has been made again towards meeting EUFAMI's important strategic goals.

One of our main priorities in 2018 was to deepen EUFAMI's engagement and sphere of influence with the different stakeholders engaged in mental health at European level. As part of this work EUFAMI representatives attended various EU level meetings, including representing EUFAMI and speaking on behalf of families and family carers at the meetings of the European Parliament Interest Group on Mental Health, Well-being and Brain Disorders. In addition, the views of families and informal carers were represented by EUFAMI at the World Health Organisation (WHO) Collaborating Centre at an event dedicated to Research and Training in Mental Health and also at a high level Workshop on Mental Health Performance organized by the Organisation for Economic Co-operation and Development (OECD).

2018 also saw continued work, with the London school of Economics, as we made progress on our Economic Case for Caring project. The research results from this project (based on a survey carried out in 8 countries) will provide valuable information to all interested stakeholders, including policy makers. We hope that the results of this project will raise awareness on how care provided by family members and other unpaid carers is an important element of

European mental health systems, and raise awareness of the cost if all of this 'informal' care had to be replaced with formal mental health services and support. Once the results are published in late 2019, EUFAMI hopes to use the findings to further support ongoing advocacy work on behalf of all families affected by mental ill health.

Once again through our work in the various EU projects we are involved in, EUFAMI ensured the family aspect was taken into consideration. PRISM, MENS, EU-viormed and PECUNIA are some of the EU projects we contributed to in 2018.

Publications are another way in which we support families and help raise awareness, and this year we contributed to 'A sustainable approach to depression: moving from words to actions' and started working on the 'Carer playbook' which is being developed to help improve the lives of families affected by mental ill health.



Miia Männikkö, President

Cooperation with other European organisations was strengthened this year, with EUFAMI and the European Psychiatric Association (EPA) forging closer ties and the EUFAMI President attending EPA's Board Meeting as a newly elected member.

This year the theme of World Mental Health Day was 'Young carers' and EUFAMI engaged with this future oriented topic via a campaign on social media. In addition, EUFAMI was invited to speak at EPIONI's conference on the topic of 'Young carers in a changing world'.

2018 EUFAMI committed itself to working more closely with its members by preparing EUFAMI's strategy for the years 2019-2021. We also worked together to develop our Manifesto to increase awareness of the needs of families, and the challenges they face, in candidates to the EU elections. We also continued to organise face-to-face meetings with our member organisations, such as the cluster meeting we had with our members in Greece or the interaction we were able to have with our member in Spain.

Social media continues to be a very much appreciated method of communication, and in 2018 we focused our efforts on Twitter, where we saw a consistent growth and interaction in our followers.

May I end by renewing our thanks and good wishes to all those who connect and collaborate with EUFAMI as members and partners, or as individuals. It is always worth remembering that we gain strength by working together.

2018 AT A GLANCE:

JANUARY

- ★ **14 - 15** EUFAMI Vice President attends PECUNIA project kick-off meeting in Vienna
- ★ **17** Board Member attends, as an observer, the Internal Meeting of European Expert Group on Deinstitutionalisation in Brussels
- ★ **23** Board Member represents EUFAMI at the Report launch event of the High-Level Task Force on investing in Social Infrastructure in Brussels
- ★ **30** EUFAMI Executive Director attends the 2nd "What If" policy roundtable on overcoming the ethical challenges of early detection and diagnosis of Alzheimer's disease. The meeting was hosted by Sirpa Pietikäinen MEP and Nessa Childers MEP, and was organised with the support of MSD

FEBRUARY

- ★ **1** Executive Director attends the Annual Convention for Inclusive Growth – ACIG 2018, organised in Brussels by DG Employment, Social Affairs

and Inclusion. The meeting focused on "The European Pillar of Social Rights: on the road to implementation"

- ★ **8-9** EUFAMI Executive Director represents EUFAMI at DG Sante's Third EU Mental Health Compass Forum meeting, and the 4th European Community Based Mental Health Service Providers (EU-COMS) meeting. Both meetings were held in Luxembourg
- ★ **22** EUFAMI Board of Directors have their first meeting of the year in Leuven

MARCH

- ★ **1** Executive Director represents EUFAMI at the Selfcare Initiative Stakeholder meeting in Brussels
- ★ **3-6** EUFAMI Vice President speaks at the 26th European Psychiatric Association (EPA) Congress in Nice
- ★ **6** Executive Director participates in the European Parliament Informal Carers Special Interest Group meeting. The focus of the meeting was young carers, the challenges they face and the actions

that need to be taken to address these

- ★ **7** Executive Director attends the GAMIAN Europe Workshop on Improving empowerment and self-management of care in mental health. The workshop was held at the European Parliament in Brussels
- ★ **8-9** Executive Director represents EUFAMI at the 3rd PRISM project General Assembly
- ★ **13-15** Executive Director represents the voice of informal carers at the 16th Eyeforpharma annual conference in Barcelona
- ★ **29-30** Executive Director is a plenary speaker on the subject of "Challenges for citizens in the mental health system" at the World Health Organisation Collaborating Centre for Research and Training in Mental Health in Lille, France

APRIL

- ★ **14-15** Executive Director represents EUFAMI at the European Patients Forum (EPF) Annual General Meeting in Brussels

★ **17** A EUFAMI delegation (Vice President, Board member and Executive Director) attend the seminar “The Social Pillar and European Semester as tools for delivering social Europe – a reflection with civil society”, organised by DG Employment, Social Affairs and Inclusion in Brussels

★ **27** Executive Director and Board member represent EUFAMI at the Annual Convention for Inclusive Growth (ACIG) - “The European Pillar of Social Rights: on the road towards implementation”. The Convention was held in Brussels

MAY

★ **16** Executive Director, accompanied by a Board member, speaks at a meeting of the European Parliament’s Special Interest Group of Mental Health, well being and brain disorders. The topic of the meeting was “Empowerment of patients affected by Mental Health Conditions and their self-management of care

and treatment”. The meeting provided an opportunity for the launch of a Call to Action on the topic

JUNE

- ★ **1** Second meeting of the EUFAMI Board of Directors in Leuven
- ★ **2** EUFAMI member associations representatives attend the Annual General Meeting and Member Participation day in Leuven
- ★ **3** Continuation of the second meeting of the EUFAMI Board of Directors in Leuven
- ★ **27-28** President and Executive Director attend the 1Voice! Global Patient Advocacy Summit in Copenhagen

★ **29** President presents the Carer perspective at the high-level OECD Workshop on Mental Health Performance. The workshop was held in Paris

JULY

★ **3** Executive Director represents EUFAMI at the Open

meeting of the European Expert Group on Transition from Institutional to Community Care. The meeting, held in Brussels, focused on the next EU Funding regulations

SEPTEMBER

- ★ **5** Meeting of the Economic Value of Caring Advisory Board at the EUFAMI offices in Leuven
- ★ **12-13** Executive Director attends the PRISM project Scientific Committee Meeting in Leiden
- ★ **19** Executive Director represents EUFAMI at Finnish Permanent Representation Seminar on Mental Health. The meeting was held in Brussels
- ★ **21** EUFAMI Treasurer attends the “Stakeholder Cooperation on Depression” meeting in Brussels
- ★ **20-23** Executive Director joins the EVENTS Project’s 1st *European Sport & Physical Exercise Event for Mental Health*, in Athens, Greece, which was organised by EDRA

2018 AT A GLANCE:

- ★ **24-25** Executive Director moderates breakout group III's discussion on Dissemination, Outreach & Partnerships of the European Brain Council's Strategic Workshops
- ★ **27** Third meeting of the EUFAMI Board of Directors in Athens, Greece
- ★ **28** Board members and Executive Director meet with representatives of EUFAMI's Greek member associations at the European Parliament Offices in Athens, Greece
- ★ **28** EUFAMI's President delivers speech at EUFAMI member EPIONI's conference "Young Carers in a Changing World" which was held in Athens, Greece

OCTOBER

- ★ **2** Executive Director attends the "European Pillar of Social Rights and European Semester as tools for delivering Social Europe" seminar organised by the European Commission's DG for Employment, Social Affairs and Inclusion in Brussels

- ★ **6-9** EUFAMI has exhibition booth at the 31st ECNP Congress in Barcelona
- ★ **8-10** Executive Director attends the 2nd Meeting of the EU-VIORMED Project Leaders in Dusseldorf, Germany
- ★ **18** Treasurer speaks about EUFAMI's role and activities at the Cavan/Monaghan Mental Health Service Conference in Cavan, Ireland
- ★ **18** Executive Director attends the Self Care Initiative Europe Task Force's meeting in Brussels
- ★ **29** Executive Director is moderator at the Psychosis and Schizophrenia Patient and Carer Roundtable in Brussels
- ★ **30** Executive Director represents EUFAMI at the Workshop "Headway 2020" at the Ministry of Health in Rome at which the state of the art in the management of patients with severe ill mental health was discussed
- ★ **31** EUFAMI Board member participates at the European Patients Forum Working Group "Universal Access to Healthcare" meeting in Brussels

NOVEMBER

- ★ **6-7** EUFAMI President and Executive Director are invited to speak at the EU Patient Advocacy Summit in Brussels
- ★ **13** Executive Director represents EUFAMI at the European Expert Group on Deinstitutionalisation Meeting in Brussels
- ★ **15** Executive Director participates at the Strategic Dialogue meeting "Implementation of the Council Recommendation on the integration of the long-term unemployed into the labour market", organised by DG for Employment, Social Affairs and Inclusion's Civil Dialogue team in Brussels
- ★ **16** EUFAMI Board member represents European family carers' views at the International Association of mutual benefit societies' Congress "The Future of Mental Health – Promotion and Disease Prevention". The Congress was held in Brussels
- ★ **21** Executive Director speaks at the Special Interest Group on Carers meeting at the European Parliament. Topic

is the EU Work/Life Balance Directive and the European Pillar of Social Rights – New Impetus for a comprehensive EU Carers’ Strategy

- ★ **22-23** EUFAMI’s President is invited to speak at the Final conference of the Pilot phase of Spanish Member Salud Mental Catalonia’s project "Activa’t per la Salut Mental”
- ★ **22-23** Executive Director attends the COFACE expert Seminar on Economics at the service of Society
- ★ **29** EUFAMI President and Executive Director represent EUFAMI at the EU Health Summit 2018 – A shared vision for Mental Health in Brussels
- ★ **30** fourth EUFAMI Board of Directors Meeting in Leuven

DECEMBER


- ★ **3** EUFAMI President speaks at the European Parliament Special Interest Group on Mental Health Wellbeing and brain disorders. Theme of the meeting is "New Horizons for person centred mental health research and care"
- ★ **3-4** EUFAMI President attends European Psychiatric Association (EPA)’s Board Meeting as newly elected member
- ★ **5** President and Executive Director join launch of "A Sustainable approach to Depression: moving from words to actions" report in the European Parliament
- ★ **5-8** EUFAMI’s Vice President speaks at EUFAMI Member METIS’ European Conference in Nice

EUFAMI STATS 2018



4 351
FANS
-52
NEW FANS

3 225
FOLLOWERS
+ 125
NEW FOLLOWERS



+ 174
2 624
NEWSLETTER READERS




45
EU MEETINGS

5
PROJECT MEETINGS

6
EUFAMI MEETINGS
(4 Board Meetings, 1 AGM,
1 Cluster meeting)

MEMBER FOCUS



AGMI – KIPRODIPSA (Cyprus)

During 2018 AGMI continued, with commitment, its core advocacy work promoting mental health, by raising awareness of the mental health issues faced by people affected by mental ill health and/or psychosocial disabilities, and their families and carers.

AGMI's activities were aimed at different stakeholders such as decision makers of different ministries, services and departments.

In February 2018 an event was organized in partnership with the Medical Museum Kiriazzi to promote mental health information, sensitise the community, and promote advocacy. Invited speakers on this subject were psychiatrist Georgios Mikelides and Clinical Psychologist Anna Kyriakou.

The event, one of AGMI's advocacy endeavours, was held under

the auspices of Mrs Skevi Koukouma, Parliamentary Deputy President of the Committee of Labour and Welfare and of Parliamentary Committee member of Health Mr Georgios Procopiou.

BGFAMI (Bulgaria)

In 2018, BGFami was involved in two important events:



In cooperation with representatives of the Bulgarian Mental Health Experts, BGFami initiated and organised a round table with a press conference at BTA - a national news agency. The event was BGFami's first major public appearance with the purpose of drawing attention to the critical issues in psychiatric healthcare in Bulgaria. The Round Table was mentioned in national printed and electronic media, and as such is a first step in the efforts to engage and change state policies, to understand family carers' perceptions of good

psychiatric care, and ultimately to realise the right to a good quality life in the community of people with mental ill health.

BGFami was also the Bulgarian partner in the establishment of a "College of Empowerment", which is being carried out in cooperation with five other European organisations (from Germany, the United Kingdom, Italy, Poland and the Netherlands) within the framework of a two-year Erasmus+ funded initiative. The project targets vulnerable groups and aims to increase their autonomy, promote education and the labour market, and reduce the use of social services in the community.

EDRA (Greece)

KSDEO EDRA, in its capacity of Coordinator of the EVENTS Project, organized the 1st European Sport & Physical Exercise Event for Mental Health, which took place in Athens, Greece, from 21st to 23rd September. The project's activities clearly demonstrated its initial aim: the positive influence of sports and physical exercise on mental health.

For 3 days, volunteers, coaches, recipients of mental health services, staff and participants



from the general public played together and shared their experiences, finally gaining a sense of emotional satisfaction through sports and physical exercise, dance and artistic activities. The event counted 377 participants, 35 organisations from 14 countries, 17 coaches, 55 volunteers, 24 activities.



ENCONTRAR+SE (Portugal)

ENCONTRAR+SE had a very fruitful 2018 providing support to people with mental illness and their families in Porto. They continued their action to fight stigma in mental health with "Vozes de Esperança" (Voices of Hope), a group of people with mental illness and family members that share their stories in schools, hospitals, etc. In addition, ENCONTRAR+SE was proud to launch "Ouvir o que não é dito. Primeiros Socorros na Doença

Mental", (Listen to what is not being said. Mental illness first aid), a course developed with the support of Time to Change and Mental Health First Aid England, aiming to improve the ability to deal with mental illness in the workplace. For more information see www.encontrarse.pt.

EPIONI (Greece)



On September 28th, 2018, EPIONI organized at the office of the European Parliament in Athens, a conference focusing on young caregivers. The event was held under the auspices of the Ministry of Health in Greece, the World Federation for Mental Health, the Hellenic Psychiatric Association, EUFAMI and the European Brain Council. In the conference, prominent scientists provided insights about long term care. The event which had the support of the European Parliament office in Greece and the European Commission Representation in Greece gave the opportunity to caregivers to share their personal experiences and discuss the challenges involved in caregiving.

FINFAMI (Finland)

FinFami was campaigning largely in the themes of carers with mentally ill family members by, amongst others, highlighting the roles of carers in the main media channels in Finland with the purpose of reaching many decision makers and politicians. Every year FinFami organises a National Day for Family Members and Carers with Mental Issues. The theme for 2018 was Child Carers: #DoNotCloseYourEyes. FinFami launched a video for the campaign: <https://www.youtube.com/watch?v=P2SizedUf-Q>.

FinFami also ran a number of Prospect Courses and counted 88 participants in the Module for Families and Friends. Young family members have very actively participated in the Prospect-programme. FinFami and the Schizofreniförbundet Sweden also started a collaboration to launch the Prospect-programme for Finnish speaking carers in Stockholm.



MEMBER FOCUS

HAFAL (Wales)

2018 was a great year for Welsh mental health charity Hafal. During the summer their national campaign - 'Deeds Not Words' - was run which focused on women's mental health and the inequality they still face 100 years since women were given the right to vote. The campaign was a huge success in raising the key mental health issues that women face today. 2018 also marked the first full year of Hafal's Mental Health and Money Advice team, which has gone from strength to strength. The team supports people with a mental illness and their carers with financial issues such as debts and benefit payment problems and they have managed to save clients over £1 million! Hafal also ran two Physical Health Awareness days which are now held in both South and North Wales. They were attended by over 400 service users and carers and in the Swansea event we were joined by players from Swansea City Football Club and Ospreys Rugby Club.

For more information on Hafal's activities please visit www.hafal.org or follow them on social media.

HPE (Austria)



The past year, 2018, marked a big anniversary in the history of HPE, Austria - 40 years of self-help. This was duly celebrated in October in Vienna and Joy Ladurner, a former Board Member of EUFAMI, led through the evening in her usual lively manner. All the previous Presidents were present including some founder members - Mag. Ingrid Rath, Dr. Heinz Katschnig and Dr. Maria Simon at the grand age of 100 years! Shortly after this, the seminar for group leaders, with a focus on the problematic of communication under the title "How can I say it?" an ever-present topic in mental health issues, was a great success.

In the Salzburg branch of HPE, AhA! Mag. Gottfried Zlanabitnig took over the chair from the long-standing president of 18 years, Sigrid Steffen, well-known to EUFAMI members because of her 7-year membership of the Executive Committee and her Presidency of EUFAMI up until 2011.

MindWise (United Kingdom)

In 2018 MindWise were delighted to have been awarded the Gold Investors In People (IIP) Award and also the Investors in Wellbeing Award. These awards were a reflection of the hard work and effort of all of the MindWise staff, and the continued investment MindWise make in their people.



Rethink Mental Illness (United Kingdom)

In 2018, Rethink Mental Illness focused on turning increased awareness on mental health into action to improve the lives of people severely affected by mental illness and their carers. Our report "Right Treatment, Right Time", featuring a ground breaking survey of over 1,600

people's experiences of care and treatment, set out a clear picture of the significant gap in access to health services. In tandem, a report published by the All-Party Parliamentary Group (APPG) on Mental Health, which Rethink Mental Illness serves as the joint secretariat, concluded that core services are all but overwhelmed for lack of resources.

This work helped sharpen the focus of the new NHS England Long-Term Plan, which provides much needed new resources for improving care and support for people severely affected by mental illness – all being equal we expect to see unprecedented investment in severe mental illness across the NHS over the coming ten years. This is a huge victory for campaigners such as ourselves - who have been arguing in favour of more equal treatment for mental and physical health.

In addition, Rethink Mental Illness played a key role in the delivery of the Independent Review of the Mental Health Act and successfully campaigned for a U-turn in the government's proposed changes to supported housing.

On a European stage we are involved in the Learning4Carers project and were able to share our experience as one of the larger carers' organisations in Europe at the meeting hosted by Greek Carer's network EPIONI. Clearly an enormous amount of attention is taking place around

Brexit within the UK but regardless of the outcome Rethink is committed to keeping close ties with colleague organisations across Europe.

Salud Mental (Spain)

In 2018 Salud Mental launched their webpage "Diversamente" (<https://diversamente.es/>) a project managed by 'Pro-Mental Health in the First Person Committee'. This Committee is formed by people with mental health problems who actively participate in the life of the Confederation and who believe in the motto "nothing about us without us", on the basis that the experience itself provides a fundamental point of view when analysing and defending the rights of this group and their families. With the creation of the Committee, the strong commitment of the governing bodies of the Confederation to promote and facilitate the real participation of people with mental health problems in their functioning and decision making is materialised.

SHINE (Ireland)

In November 2018, Shine launched its Strategic Plan for 2019-2021.

This strategic plan builds on our previous plans which have led the organisation in its achieve-

ments to date. Since late 2017, Shine has engaged in a number of focused activities to inform them on the development of this new strategic plan. These activities include a review of our current support group activities, a series of stakeholder meetings involving staff, facilitators, Shine members and board member workshops.

The four objectives under the new strategic plan are:

1. To provide appropriate and timely information and education as required to support recovery for all family members.
2. To lead in the promotion of the right to person centred and appropriate recovery orientated services.
3. To be a leader in initiating and participating in research and innovation to inform knowledge of recovery, policy and practice.
4. To be a key influencer in the development of national mental health service policy and practice and the reduction of stigma and discrimination.

Over the coming years we aim to consolidate and improve the national reach of our work. We will research new areas of work to identify best practice in recovery-orientated service delivery for all family members.

Please [click here](http://bit.ly/Shine_Strategy) (http://bit.ly/Shine_Strategy) to view Shine's Strategic Plan 2019-2021.

EUFAMI STRATEGY 2016-2018

EUFAMI is a not for profit Federation, comprised of national and regional family organisations from across Europe.

Mission

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

Vision

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

Values

The central role and rights of family members in the care and treatment of people with mental ill health should be fully acknowledged and provided for throughout Europe.

Family carers should be acknowledged as equal partners with professional staff and the person with mental ill health in decisions relating to the planning and delivery of treatment and care.

Families and individual family members have a right to choose and define the role they are willing and able to play. This must include the right not to be involved directly with their relative's care, or to be involved in planning services, campaigning and monitoring services. State mental health care should be adequate to enable family members of people with mental illness to make their choice without regard to any feelings of personal obligation.

Families should not be discriminated against or held responsible legally or financially for their family member directly affected by mental ill health.

People with mental illness should be cared for in an appropriate environment and provided with all necessary health and social services.

The needs of all family members for support and understanding should be recognised and fully provided for.

It is the human right of all people with mental illness and their families to share as fully as they can in the opportunities, enjoyments and responsibilities of everyday living.

Aims and Objectives

- ★ To support member associations in their efforts to improve standards of treatment, care and quality of life of people with mental illness and their family carers and friends.
- ★ To engage in the development of family movements in countries where such movements are currently weak or do not exist.
- ★ To involve member associations closely with the development of EUFAMI activities.
- ★ To help member associations combine their efforts at regional and European levels and to reach out to promote the aims and objectives of families.
- ★ To deepen EUFAMI's influence and enhance its reputation with key international bodies, clinical associations and healthcare professionals to ensure that the concerns of family carers are always fully recognised.
- ★ To lobby European policy makers to continue their efforts to improve mental health and social care services as a human right in each member state so that a more equitable situation will result across the continent.
- ★ To campaign for adequate resources to be provided for services and support for people with mental illness and their families.
- ★ To identify examples of good practice in the field of mental illness and communicate them appropriately throughout Europe.
- ★ To promote and, where appropriate, participate in research into the causes and management of mental illness and its treatment.
- ★ To engage in public awareness programmes and campaign for changes in public attitudes so as to help remove stigma and discrimination against people with mental illness and their family carers.
- ★ To develop and strengthen partnerships between EUFAMI and other organisations having purposes and objectives which are similar to those pursued by EUFAMI.
- ★ In all ways to defend the rights of people with mental illness and their families.

For 2018 EUFAMI had three broad strategic objectives

1. TO EXPAND OUR MEMBERSHIP INTO CENTRAL AND EASTERN EUROPE
2. TO INVOLVE AND SUPPORT ALL OUR MEMBERS MORE CLOSELY
3. TO DEEPEN OUR INFLUENCE WITH KEY INTERNATIONAL AND PROFESSIONAL ORGANISATIONS AND POLICY MAKERS.

PROJECTS

Economic Value of Caring:



This is a new project which builds on our Caring4Carers survey by looking at how unpaid care provided by family members and other informal carers is an important element of any mental health system, yet too often the contributions are not fully recognised or appreciated. Policymakers are unlikely to be aware of the extent of the cost if they had to replace all of this family or informal care with formal mental health services and support.

EUFAMI, in collaboration with the London School of Economics, is looking to obtain credible evidence on the economic contribution of family/informal carers of persons with severe mental ill health (in particular schizophrenia, bipolar disorder and major depression) in order to have compelling evidence to share with policy makers at European and national levels to encourage investment in policies and services which support family/informal carers.

The results of the Economic Value of Caring project will be available in late 2019. More information can be found at <http://eufami.org/economic-case-survey/>.

MENS Project

EUFAMI is partner in the EU Erasmus+ project MENS (Mental health European Network of Sports). Under the leadership of EUFAMI affiliate member EDRA, this project brings together 17 partners from 12 countries interested in promoting mental health through social inclusion in “every day” activities, in this case sports. To this purpose, a series of policy papers was developed in order to provide a comprehensive and argument, justifying the contribution of sports, physical activity and exercise for the prevention, therapy and rehabilitation of people suffering from mental ill health in Europe. In 2018 the project partners also launched an awareness campaign called ‘Life is a Bike’.



The project was concluded by a final conference in June in Athens where all the initiatives and actions developed within the project’s implementation were presented.

EUFAMI’s role was to lead the work stream on networking, overseeing the mapping of key stakeholders at EU and national levels in each of the EU Member States.

Further information about the MENS project can be found at <http://eufami.org/our-projects/>.

EU-VIORMED



EUFAMI is a partner in the European Study on Violence Risk and Mental Disorders (EU-VIORMED) project. EU-VIORMED is an EU-funded project working on improving and standardising forensic psychiatric care across Europe.

The project is examining best practice in 5 European countries (the UK, Germany, Austria, Poland, and Italy) with a focus on generating new data on violence and self-harm

assessment. It will also attempt to formulate recommendations to assist in the planning of services for clinicians, managers, commissioners and politicians.

The kick-off meeting from 13 – 15 November 2017 in Brescia, Italy was followed by an AGM in Duesseldorf in October 2018 with monthly teleconferences to discuss progress made so far.

In this project EUFAMI is involved in communications and dissemination. Please see <http://www.eu-viormed.eu/> for more information.



PRISM

PRISM aims to find new treatments for the three most common brain disorders in Europe: Alzheimer's disease, schizophrenia and major depression. It does so by looking at a symptom these three diseases have in common – social withdrawal – and investigating whether there are biological markers for this symptom which new drugs could target to reduce symptoms

and improve quality of life. Social withdrawal feeds stigma, which impacts not just patients but entire families. Tackling social withdrawal therefore has enormous potential for positive impact. EUFAMI contributed to the research protocol and organised a members' focus group gathering families' experiences with symptoms of social withdrawal in schizophrenia. Results of the members' focus group gathering were presented at the Project AGM held in London.

<http://prism-project.eu>

The PRISM project is funded by IMI JU which receives support from EU H2020 and EFPIA.

PECUNIA

Programme
in Costing,
resource use
measurement



and outcome valuation for Use in multi-sectoral National and International health economic evaluations: PECUNIA aims to tackle the healthcare challenges of an ever-growing and rapidly ageing population in the EU

by developing new standardised, harmonised and validated methods and tools for the assessment of costs and outcomes in European healthcare systems.

Comparing and exploiting data across different countries and sectors, PECUNIA aims to provide direct comparable solutions to improve chronic and mental healthcare in all EU health systems.

EUFAMI is a member of the PECUNIA Advisory Board.

UPCOMING PROJECTS

CARER Playbook

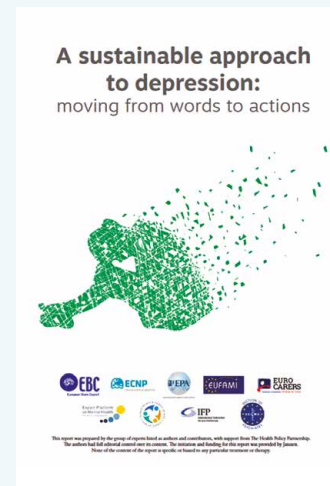
In 2018 EUFAMI started work on the Carer Playbook, a tool which will provide guidance and advice to carers of those living with schizophrenia, helping them to navigate the struggles they may face. The tool is scheduled to be launched in early 2019.

PUBLICATIONS

A sustainable approach to depression: moving from words to actions'

This joint report was launched by 9 high level mental health and brain health related organisations who advocate for a comprehensive and sustainable policy response, which should have a holistic approach. In addition, it should focus on the entire spectrum of depression, ranging from prevention and early diagnosis to better management and prevention of suicide. The report draws from the practical experiences of a variety of innovative projects addressing different aspect of depression across the EU. It lists key factors and findings which can help policymakers develop and put in place concrete, relevant and sustainable policies and initiatives,

summarised in 10 practical recommendations. These include the need for integrated services, a focus on young people, a whole family approach, a positive work environment and joined up policies on suicide. The full report as well as an executive summary can be downloaded from the EUFAMI [website](http://eufami.org/resources/) (<http://eufami.org/resources/>).



For more information on any of these and more recent projects, please visit <http://eufami.org/our-projects/>.

FINANCIAL REPORT

Audited Financial Results 2018

For the year 2018, **income** received in support of EUFAMI's core operations, comprising of funds mainly from corporate donors, projects and membership fees, amounted to €148,942.

Expenditure for the same year amounted to €177,004 - the main items being staff and office costs, financial services and general overheads including Board and General Meetings.

The **net result** was a negative balance of €28,062.

Balance sheet

Assets		2018	2017
	Fixed assets	183	1069
Plant, machinery & equipment		183	1069
Furniture			
Other tangible assets			
	Current assets	169866	184434
Trade debtors		13082	3508
Other amounts receivable		0	0
Cash at bank and in hand		154133	179655
Transitory accounts		2651	1271
Total assets		170049	185503
Liabilities		2018	2017
	Capital and reserves	56618	84680
Allocated funds		44294	44294
Profit carried forward		40386	38491
Profit of the year			1877
Loss of the year		28062	
Creditors			
Trade debts		14109	5689
Staff debts		9322	34110
Transitory accounts		90000	60844
Total liabilities		170049	185503

Income and Expenditure

Income €	2018	2017
Membership fees	12575	12450
EUFAMI Collaborating Partner Programme	65000	55000
Project funding	54609	113668
Recovered expenses/Honoraria/Other	8291	4848
Financial income	41	2640
Own fundraising activities	7000	0
Extraordinary income	0	50340
Staff subsidy	1426	0
Total income	148942	237480
Expenditure €	2018	2017
Board of Directors	13643	9693
General Meeting	3963	3198
Staff Costs	76730	163541
Write off trade debtors	3112	2485
Office/insurances/suppliers	11418	15284
Annual report/Communications	3589	6423
Website/promotion/representation/IT Costs	6752	4630
Finance and legal expenses	15244	17360
Misc. costs including depreciations	1304	2132
Project expenses	41249	10971
Extraordinary charges		-112
Total Expenditure	177004	235605
Profit/Loss	-28062	1877
Detail of Income		
1. Core (Collaborating Partner Programme)	2018	2017
Janssen	30000	30000
Lundbeck	25000	25000
Boehringer Ingelheim	10000	25000
Total	65000	80000
2. Projects	2018	2017
IMI PRISM project	620	5145
EUFAMI25	40	4765
MENS	8725	9299
EU VIORMED	5224	2355
Lundbeck Otsuka Alliance - Economic Case	20000	20000
Janssen - Carers Playbook	20000	
Lundbeck Otsuka Alliance - Caregiver Initiatives		25000
EBC Value of Treatment		1530
Lundbeck US Outreach Programme		30000
Lundbeck - Caring for Mental Health in the Workplace		8008
Boehringer Ingelheim - Schizophrenia Advisory Board		6100
Total	54609	113668

Audited Accounts Commentary

I took over the role of Treasurer mid way through 2018 from my predecessor Bert Johnson. The year has been a challenging year for EUFAMI in a number of ways, including its financial position. Total operating income in 2018, as mentioned earlier, amounted to €148,942 while total expenditure for the year was €177,004, resulting in a loss of €28,062 for the year.

The main reasons why the loss has been incurred are basically two fold - firstly the commencement of our main project, the 'Economic Case for Carers', was delayed; this resulted in our inability to recognise associated income from this project in 2018. Secondly, there were unavoidable increases in the forecasted costs for some of EUFAMI's operational items.

Reporting a loss is not a situation which we like to find ourselves having to do. It should be noted that it is not unusual for EUFAMI to incur a loss - in many of the previous years EUFAMI has also had to report a loss. The obvious effect of incurring a loss is that our financial reserves are reduced by the amount of the loss. While we still have a positive cash reserve at our bank accounts, this loss making trend cannot continue indeterminably.

The once steady and reliable funding which EUFAMI received from its Partner Programme has been decreasing year on year. Our funding partners are themselves experiencing major pressures. It should also be noted that EUFAMI is not unique in this situation, as many of our fellow NGO/voluntary bodies in Brussels (European umbrella bodies) are also experiencing difficulty in securing unrestricted funding.

The Board is acutely aware of this position and is making every effort to correct this situation. Much Board time is being dedicated to this matter, and we are undertaking cost reductions and exploring other income-generating alternatives. It is our intention to have some of these corrective measures reflected in our Budget for 2019 in an effort to correct the financial position and bring it back to, at best, a break even point for 2019.



Kevin Jones
EUFAMI Treasurer

"EUFAMI needs your donations to keep supporting families and combat stigma. You can donate directly to our account or through Paypal."

ACCOUNT DETAILS: IBAN BE41 0011 98562110

EUFAMI is grateful for the financial support received from the following sponsors:



GOVERNANCE

ANNUAL GENERAL MEETING



The Annual General Meeting (AGM) is EUFAMI's highest decision-making organ. Held once a year, the AGM approves new members and finances, and elects the Board of Directors. The 2018 assembly took place in our "home town" of Leuven on 9th June and elections were held for two Director positions. Friedrich Leidinger from BApK in Germany and Edo Belak from SENT in Slovenia were elected to the EUFAMI Board of Directors.

BOARD OF DIRECTORS

EUFAMI is governed by its Board of Directors which meets four times a year. The Board sets out the strategic direction of the organisation and oversees the work of the Secretariat.

Our Board of Directors are all non-remunerated volunteers, elected by the Annual General Meeting.



SECRETARIAT

The Secretariat implements EUFAMI's strategy, with the guidance of the Board, and is responsible for the day-to-day running of the organisation.



MARGARET WALKER,
Executive Director



RITA GEERTS,
Administrator

In 2018 the Board of EUFAMI consisted of:
(pictures from left to right and top to bottom)

- ★ **MIIA MÄNNIKKÖ,**
President, FINFAMI, Finland
- ★ **MARTINE FRAGER-BERLET,**
Vice President, UNAFAM, France
- ★ **PER TORELL,**
Secretary, Schizofreniförbundet, Sweden
- ★ **KEVIN JONES,**
Treasurer, Shine, Ireland
- ★ **SPYROS ZORBAS,**
Officer, EPIONI, Greece
- ★ **ANDRÉ DE CRAENE,**
Officer, Similes VI, Belgium
- ★ **EULALIA PEREIRA,**
Officer, ENCONTRAR+SE, Portugal
- ★ **BERT JOHNSON,**
Treasurer, Rethink Mental Illness, UK (retired June 2018)
- ★ **KENNETH LIEN STEEN,**
Officer, Norway (retired June 2018)
- ★ **FRIEDRICH LEIDINGER,**
Officer, BApK, Germany (elected June 2018)
- ★ **EDO BELAK,**
Officer, SENT, Slovenia (elected June 2018)

ACKNOWLEDGEMENT

In June 2018, Bert Johnson and Kenneth Steen retired. Bert had reached the end of his third and final term on the Board, and Kenneth retired after the end of his first term. Bert joined the (then) EUFAMI Executive Committee in 2009. He held the position of President from 2012 until 2016 and was Treasurer from 2016 until 2018. Kenneth was member of the Board from 2015 to 2018.

We are most thankful to them for their valuable contributions to EUFAMI, both in their capacity of members of the Board of Directors, but – both dashes of equal size - as carers, representing EUFAMI on many occasions.

EUFAMI MEMBERS

at 31 December 2018

STATS

37 members in 23 countries

in 19 of the 28-member countries of the EU

a federation of 31 family associations and 6 other mental health associations

Full members

[ARAP](#) – Associazione per la Reforma dell'Assistenza Psichiatrica (Italy)

[Ariadne](#) – Verband Ariadne – für die psychische Gesundheit aller (Italy)

[BApK](#) – Bundesverband der Angehörigen psychisch Kranker (Germany)

[Bedre Psykiatri](#) – Landforeningen Pårørende til Sindslidende (Denmark)

[BGFami](#) – (Bulgaria)

[ENCONTRAR+SE](#) – Association to Support People with Severe Mental Illness (Portugal)

[EPIONI](#) – Greek Carers Network (Greece)

[FamiliarMente](#) – Portuguese Federation of Associations of Families of People with Mental Illness Experience (Portugal)

[FinFami](#) – Omaiset Mielenterveystyön Tukena Keskusliitto Ry (Finland)

[HPE](#) – Hilfe für Angehörige Psychisch Erkrankter (Austria)

[HUMANA](#) – Združenje Svojcev pri skrbi za Mentalno Zdravje (Slovenia)

[KINAPSI](#) – Siblings of People with Mental Health Problems (Greece)

[KIPRODIPSA](#) – Advocacy Group for the Mentally Ill (Cyprus)

[LSPŽGB](#) – Lietuvos Sutrikusios Psichikos Žmonių Globos Bendrija (Lithuania)

[MHA](#) – Mental Health Association (Malta)

[MindWise](#) (N. Ireland - UK)

[New Choices](#) (Russia)

[OZMA](#) – The National Forum of Families of People with Mental Illness (Israel)

[Rethink](#) – Rethink Mental Illness (England – UK)

[SALUD MENTAL ESPANA](#) - Confederación Salud Mental España (Spain)

[Schizofreniförbundet](#) (Sweden)

[Shine](#) – Supporting People Affected by Mental Ill Health (Ireland)

[Similes VI](#) – Federatie van Vlaamse SIMILES kringen v.z.w. (Belgium)

[SIND](#) – Landsforeningen SIND (Denmark)

[SOPSI Athens](#) – Panhellenic Association of Families for Mental Health (Greece)

[Stichting Labyrint in Perspectief](#) (Netherlands)

[UNAFAM](#) – Union Nationale des Amis et Familles de Malades Mentaux (France)

[UNASAM](#) – Unione Nazionale delle Associazioni per la Salute Mentale (Italy)

[VASK](#) – Vereinigung der Angehörigen von Schizophrenie-/ Psychisch Kranken (Switzerland)

[YPSILON](#) (Netherlands)

Affiliated members

[EDRA](#) – Services in the Mental Health and Learning Disabilities Sector (Greece)

[HAFAL](#) – for Recovery from Serious Mental Illness (Wales – UK)

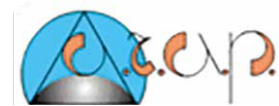
[METIS Europe](#) (Belgium)

[OZARA](#) – Nacionalno Združenje za kakovost Življenja (Slovenia)

[PEPSAEE](#) – Panhellenic Association for Psychosocial Rehabilitation and Work Reintegration (Greece)

[ŠENT](#) – Slovensko Združenje za Duševno Zdravje (Slovenia)

[SYMPATHEA](#) – Celonárodní Organizace Příbuzných Duševně Nemocných (Czech Republic)





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