



Annual report 2019



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INTRODUCTION

On behalf of my Board colleagues at EUFAMI I am pleased to introduce you to EUFAMI's activities and achievements in 2019.

The 2019 Annual General Meeting approved EUFAMI's strategy for the years 2019-2021. The strategy is based around three main pillars - *Advocacy, Membership and Research*.

The focus of the advocacy pillar requires EUFAMI to speak on behalf of family carers across Europe and as a part of this work EUFAMI successfully organised its 7th European Family Congress in September 2019. The congress was organised under the auspices of the Finnish Presidency of the EU and co-hosted by EUFAMI's Finnish member association, Mielenterveysomaisten keskusliitto - Finfami ry. The theme of the congress was '*Families and Carers at the Heart of Europe – Their Role in the Economy of Wellbeing*' and it took place in Helsinki. You can find more information about the Congress in a later section of this report and also on the EUFAMI website. I take this opportunity to thank all the participants for their commitment towards the family carers' community and a special thanks to FinFami ry for their contribution to a successful Congress.

The significance of EUFAMI Congresses is crucial within the European scene and even worldwide because there are very few regularly organised international Congresses which are focused on families of people affected by mental ill health. These EUFAMI Family Congresses provide very important opportunities to share good practices and services for family carers, research results and to meet new and previous colleagues and friends interested on the theme. So EUFAMI would like to continue to organise such Congresses into the future.

The Helsinki Declaration, titled 'The role of families and carers at the heart of Europe - their role in the economy of wellbeing', was agreed and published during the Congress and is a valuable document which needs to be translated into different languages and shared widely.

Once again, through our work in the various EU projects we are involved in, EUFAMI ensured the family aspect was taken into consideration. PRISM, EU-VIORMED and PECUNIA are examples of some of the EU projects we contributed to in 2019.

The second pillar of EUFAMI's strategy is membership and as a part of this work EUFAMI commenced its Prospect Plus project in 2019; the objective of this work is to update the Prospect programme for families and friends. The original programme was developed almost twenty years ago and the value of the programme has been demonstrated clearly by a number of EUFAMI member organisations who have very actively delivered the programme in their countries and via some national intervention surveys. This programme provides very useful skills for all family members to cope with the mental ill health of their loved ones. You can find more information about the Prospect Plus programme later in this annual report.



Miia Männikkö, EUFAMI President

EUFAMI has member organisations from 24 countries and it welcomed two new countries, Hungary and Estonia, into the family community in 2019. We also continued to organise and increase greater communication with our members through the year, for example in the UK, Portugal and the Nordic countries.

Social media continues to develop as a more appropriate method for some external communication and EUFAMI gained more followers via its social media channels throughout 2019. The theme of World Mental Health Day in 2019 was 'suicide prevention' and EUFAMI engaged with this topic via a social media campaign.

The third strategic pillar is research and as a part of this work EUFAMI continued its 'Economic case for caring' research; this entered its final phase in 2019 when Prof. David McDaid from the London School of Economics presented the preliminary results of 'The Economic Case for Caring' at the EUFAMI Congress. In summary it was found that the hours spent caring are huge and the experience of loneliness is quite common amongst the family members. The final results will be communicated and disseminated more widely during 2020.

I take this opportunity to thank EUFAMI former Board member Martine Frager-Berlet for her valuable contributions to EUFAMI as well as EUFAMI's recent Executive Director Margaret Walker for her interest and commitment to develop EUFAMI as it moves forward.

Finally I thank you and wish continued good health to all those who connect and collaborate with EUFAMI and members as partners or as individuals. It is worth remembering that together we are strong.

2019 AT A GLANCE:

JANUARY

- ★ **23** EUFAMI's Executive Director attends an extra Steering Committee meeting in Brussels of the PRISM Project consortium

gration of Migrants' and 'The European Semester'. The meeting was held in Brussels

- ★ **15** EUFAMI's Board of Directors hold their first teleconference meeting of the year

- ★ **17** 2nd teleconference meeting of the EUFAMI Board of Directors

FEBRUARY

- ★ **7-8** The Executive Director represents EUFAMI at the 4th PRISM Project's General Assembly and Steering Committee meeting in Basel
- ★ **15** EUFAMI Board member attends the European Commission Directorate General of Employment and Social Affairs' Strategic Dialogue meeting in preparation of the 'Annual Convention for Inclusive Growth 2019'. The meeting was held in Brussels
- ★ **22** EUFAMI Board of Directors have their first in person meeting of the year in Leuven

APRIL

- ★ **6-9** EUFAMI's President and Executive Director are invited speakers at the 27th European congress of Psychiatry – Towards new Models, Goals and Challenges, organised by the European Psychiatric Association in Warsaw. EUFAMI also had an exhibition booth at the Congress
- ★ **11** EUFAMI Board member attends European Commission Directorate General of Employment and Social Affairs' Strategic Dialogue meeting on the Evaluation of the EU disability Strategy in Brussels.

MAY

- ★ **15** EUFAMI's Vice President, a Board member and the Executive Director participate at the 'Value of Treatment 2' Project meeting, organised by the European Brain Council. Theme is 'Case studies on Rare neurological Disorders and Mental Disorders' and the meeting took place in Brussels
- ★ **17** EUFAMI Board of Directors have their 3rd teleconference meeting
- ★ **20** EUFAMI Board member represents EUFAMI at the Annual Convention for Inclusive Growth (ACIG) – Theme of this year's convention is 'Inclusive Growth post 2020 – Looking at the future of Social Europe'. The convention is organised by the European Commission's Directorate General of Employment and Social Affairs

MARCH

- ★ **6** EUFAMI Board member attends the Strategic Dialogue meetings organised by DG Employment, Social Affairs and Inclusion. On the agenda were 'Inte-

- ★ **13-14** The Executive Director represents EUFAMI at the European Patients' Forum (EPF) Annual General Meeting (AGM) and Leadership Meeting 2019 in Brussels

JUNE

★ **13-14** The EUFAMI Executive Director and selected representatives from member associations participate at the meeting of the Advisory Board on Manic Depressive Disorder and Borderline Personality Disorder, organised by an industry partner in Mainz

★ **17** EUFAMI Board member attends the Conference on Independent Living, organised by DG Employment and Social Affairs in Brussels

★ **25-26** EUFAMI's President attends the #1Voice! Global Patient Advocacy Summit in Copenhagen

★ **27** The Executive Director represents EUFAMI at the Conference 'Bringing the Long-term unemployed back into work', organised by the European Commission and the ESF Transnational Platform

JULY

★ **4** The Executive Director and one Board member represent EUFAMI at the Strategic Dialogue meeting

on the topic of the 'European Semester, country specific recommendations', organised by DG Employment and Social Affairs

★ **5** EUFAMI Board member participates at the Internal Meeting of the European Expert Group on Deinstitutionalisation in Brussels

AUGUST

★ **21-24** 19th World Congress of Psychiatry which has as its main theme 'Psychiatry and Mental Health: Global inspirations, locally relevant action' was held in Lisbon. EUFAMI's President was invited as a panellist on the session 'Collaboration among mental health stakeholders'

SEPTEMBER

★ **7-10** EUFAMI's President is an invited speaker at the 32nd ECNP Congress in Copenhagen where EUFAMI also had an exhibition booth

★ **18 AND 21** EUFAMI has its 2nd and 3rd in person Board of Directors meetings of the year in Helsinki

★ **19** EUFAMI member associations' representatives hold their Annual General Meeting in Helsinki

★ **19-20** well over 100 delegates gather to attend EUFAMI's 7th European congress - 'Families and Carers at the Heart of Europe – Their Role in the Economy of Wellbeing' in Helsinki.

OCTOBER

★ **9** EUFAMI's President represents the family carer perspective at the Headway 2020 Forum debate – 'EU 2019 -2024: Health Champions Wanted' on the health policy challenges for the EU. The debate was organised by The European House – Ambrosetti in Brussels

★ **9-10** the Executive Director participates at the EU-Viormed Project's 2nd Annual Meeting in Firenze

★ **11-12** EUFAMI's President is an invited plenary speaker, explaining the role of family and caregivers in patient support, at the "Next Step – Symposium about the state of the art management of Schizophrenia" in Budapest

2019 AT A GLANCE:

- ★ **16** the President represents EUFAMI at the meeting of the Members of the European Parliament's Alliance for Mental Health in Brussels – subject of the meeting was 'priorities and possibilities for action'
- ★ **22** EUFAMI Board member represents EUFAMI at the Seminar 'Strengthening the Involvement of Civil Society in the European Semester', organised by DG Employment and Civil Dialogue in Brussels
- ★ **28** the EUFAMI Board of Directors holds its 4th teleconference meeting

NOVEMBER

- ★ **1** EUFAMI President takes part in the working group meeting on the EPA Label for European Quality Care meeting, a project initiated by the European Psychiatric Association and held in Brussels
- ★ **2** EUFAMI President attends the EPA Board meeting in Brussels

- ★ **12** EUFAMI Board member participates at the 'Nordic Advocacy collaboration within the field of Schizophrenia' in Stockholm
- ★ **12-14** Board member represents EUFAMI at the European Patient Forum's first Congress 'Advancing meaningful patient involvement – a path to effective health systems' which is held in Brussels
- ★ **22** EUFAMI Board member is a delegate to the "Conference on innovative and strategic partnerships toward job creation" organised by Caritas Europe in Brussels

DECEMBER

- ★ **5** EUFAMI Board member attends the 2nd Access to Healthcare Working Group Meeting, organised by the European Patients Forum (EPF) in Brussels
- ★ **6-7** EUFAMI President is an invited speaker at the 1st Congress 'Recovery'

in Portugal, organised by Associação RECOVERY IPSS. She delivered a keynote address during the opening ceremony, led a pre-conference workshop 'working with families – a European Perspective' and was a panellist intervntor, addressing 'the role and importance of Families in Mental Health - national and international Panorama'

- ★ **9** EUFAMI Board member represents EUFAMI at the 'Human Brain Project: EBRAINS community workshop' organised by the Danish Board of Technology Foundation in Brussels
- ★ **13** EUFAMI Board of Directors holds its 5th and final teleconference meeting of the year

MEMBER FOCUS

Advocacy Group for the Mentally Ill – Cyprus (AGMI)

During 2019 AGMI continued with its collective and individual advocacy activities on national and European level for citizens with mental health problems, psychosocial disabilities and their family carers, giving visibility to mental health issues, promote mental health and combat social exclusion. Through its membership of various organisations and institutions, and participation at a number of meetings and events, AGMI contributed, endorsed, promoted and disseminated positions to stakeholders.



BEDRE PSYKIATRI (Denmark)

In June 2019 the new Danish

government announced that they would seek to negotiate an agreement on a 10-year plan for psychiatric care with binding targets on, among other things, reducing the number of re-admissions, reducing waiting times and increasing the average life expectancy of citizens with psychiatric illnesses. For many years, Bedre Psykiatri has repeatedly been working for a mental health action plan that would set out long-term perspectives and work with binding goals. It is now the coming task of Bedre Psykiatri to contribute to the process in order for the action plan to become as successful as possible. Bedre Psykiatri is striving for a plan that gives people with mental illnesses a better treatment and leads to a higher rate of recovery. The association also put emphasis on recognising and supporting carers in their role in the lives of people with mental illnesses. These issues are of paramount importance for securing mental health as well as social and emotional wellbeing among all Danish people. In the coming year, Bedre Psykiatri will be keeping a strong focus on Government commitment to ensuring appropriate, effective and long-lasting mental health outcomes.

EPIONI (Greece)



EPIONI successfully organised its 3rd flagship annual event on 27th September 2019 at the office of the European Parliament in Athens focusing on informal carers and in particular on the new European directive which is of particular interest to working family caregivers. The event featured notable speakers such as professor of psychiatry George Christodoulou, Dr Dimitrios Kontis, Dr Kalliopi Panagiotopoulou, Ms Nadia Kamel on behalf of Eurocarers, Ms Donna Walsh, Director of EFNA, Professor Philip Gorwood, President of the European Psychiatric Association (EPA), and Dr Claudia Marinetti, Director of Mental Health Europe. The European dimension of support for carers was discussed in detail. The event also featured MEP Stelios Kympouropoulos and MP Marietta Giannakou who delivered a welcome speech referring to the need for implementing the new directive in Greece and

MEMBER FOCUS

for informing carers about their established rights. Mr Harris Kountouros, representing the European Parliament's office in Greece, said that the European Parliament recognises the important contribution of carers.

FINFAMI (Finland)

FinFami was the co-host of EUFAMI's Family Congress 2019 in Helsinki. The Congress was one of two official side-events of the Finnish EU High Level Presidency's Conference on the Economy of Wellbeing in cooperation with the Ministry of Social Affairs and Health of Finland. EUFAMI and FinFami held this major European Congress under the auspices of the Finnish Presidency of the EU in Helsinki, Finland on the 19th and 20th September 2019. The theme of the Congress was 'Families and Carers at the Heart of Europe' with the emphasis on 'Their Role in the Economy of Wellbeing'. The congress was relevant to all family members and persons who have experienced a mental health condition themselves, as well as all members of the medical and social professions who practice

or have an interest in the area of mental health related issues.

The Congress was made up of plenary sessions and four concurrent interactive workshop sessions. The congress provided delegates with many different insights and there was many opportunities to discuss and debate the various topics with leading experts from across all parts Europe and beyond. There were all together 200 participants from 22 nationalities at the Congress.

FinFami continued its training activities and 56 people attended the Prospect programme for Families and Friends in 2019. Young family members is a new group participating in the Prospect programme. FinFami developed the toolkit for the Prospect facilitators to multiply options on facilitating the programme also for young adults. The Prospect programme is an empowering model for families, carers and friends.



HAFAL (Wales)



After a thoroughly successful 10 years as Hafal Chair, Dr Elin Jones took on a new role as Life President as inspiring mental health and autism campaigner Mair Elliott became Hafal's new Chair.

2019 has seen Hafal launch 'Hafal's Promise', which is to provide lasting, friendly contact to everyone in its client group: Hafal celebrated this by running campaign events in each of the 22 counties of Wales, as well as events at the Principality Stadium, the Senedd and the Royal Welsh Show. Hafal was also delighted to announce former Wales and British & Irish Lions rugby star Dafydd James as Hafal's Promise Ambassador – Dafydd has tirelessly campaigned with the association to reduce loneliness and isolation, and spread our message that 'nobody in Wales need be alone'.

Hafal's fantastic Mental Health and Money Advice team celebrated two years of service in 2019 and to date have raised a staggering £1,900,000 gains for their clients in Wales. Hafal was delighted to again host its annual Physical Health Awareness Days in North and South Wales in 2019. The aims of Hafal's 'Let's Get Physical!' events are to provide people the opportunity to try sports activities, sample healthy new foods and get more information on how people with a mental illness and their carers can improve their overall physical health. These events were attended by over 500 people!

Also, in August, young clients at Hafal's Early Intervention Service took part in an amazing three-week sailing trip along the whole coast of Wales, across to Northern Ireland and the Isle of Man and finishing in Cardiff Bay. This trip helped the young people aboard develop confidence and learn key life skills.

HPE (Austria)

Membership at HPE Austria in 2019 increased by approximately 15%; additionally the number of consultations increased. This increase is as result of HPE's intensified public relations work, such as advertising and distribution of flyers.

In Vienna, self-help groups are offered, where the common factor is the family relationship to the patient - an example being groups for siblings. In other parts of the country there is not enough capacity for this. The project "Crazy Childhood" (Verrückte Kindheit) places its main focus on the fate of under-age children as well as adult off-spring of parents with mental health issues and offers invaluable help. In one part of the country there is a "Family Sponsor Project" where, once a week, the sponsors meet the child of a parent suffering from mental ill health and also support the child when the parent is in hospital.

Networking, both with state and private organisations, has been further extended and joint videos and broadcasts have been produced. There has also been an increase in the number of lectures and talks held both in schools and in Adult Education Centres.

Most of the nine provinces in Austria organise Dialogues, where there is the opportunity for patients, family members and professionals to discuss and exchange their experiences and views. Peer Groups are also on the rise, in which valuable support is offered by people who really understand. Last but not least, mobile care, in spite of many teething problems, is beginning to play a larger role, in an attempt to embrace all those people who often fall through the net.

MPTÜ-EPITÜ (Estonia)

When one needs to be with their sick loved one around the clock, there is no time for oneself. This unstable situation also has a profound impact on the health of family members of people with long-term mental ill health. Surveys that MPTÜ-EPITÜ has conducted show that chronic illnesses are worsening, depression is on the rise and somatic diseases are worsening.

In order to maintain or restore one's mental and physical health, participation in self-help groups, therapeutic intervention and certainly the organisation of social camps are very necessary. Within the framework of the projects, MPTÜ-EPITÜ has conducted seminars, lectures, camps for joint activities with family members. Self-help groups have included improving the knowledge of family members, expanding the social network and increasing the social network by participating in camps.



MEMBER FOCUS

In 2019, a trip to South Estonia to experience the natural beauty was considered the most interesting activity for family members.

A guide, experienced in the culture of folk music, accompanied the group. He played shaman drums and all participants sang to improve their health and the health of their loved ones. The guide had prepared stories of local legends of interest to the herdsmen. The group also visited old castles and listened to legends of old stories.

Rethink Mental Illness (England)

In 2019, and against a backdrop of wider political turmoil in the UK, Rethink Mental Illness kept up the pressure to improve the lives of people severely affected by mental illness and their carers. Promoting greater rights, and via a petition signed by almost 5,000 supporters and a successful lobbying campaign at the December General Election, Rethink Mental Illness secured a commitment from the three main political parties

to reform the outdated Mental Health Act (with a White Paper and draft legislation now set to be published in the autumn of 2020). Leading the way on community care, Rethink Mental Illness published its Communities that Care Report, which raised awareness about the lack of wider community support and set out a model of care that brings together housing, employment and support for physical health. Championing the voice of carers, Rethink Mental Illness was one of the seven official partner charities of Carers Week in June, drawing attention to the social isolation faced by millions of unpaid carers. Finally, Rethink Mental Illness was proud to launch its brand new website in 2019, which enables people to access their award winning factsheets on their mobile, tablet and PC.



Salud Mental España (Spain)



On Friday, 19th July 2019 at the Palacio de La Zarzuela the Spanish Queen, Letizia Ortiz, received the 'Women's Network in MENTAL HEALTH SPAIN', and learnt first-hand about their claims, aspirations and objectives for the future in the medium and long term. At the meeting, the women conveyed to Her Majesty the main concerns that motivated the creation of the Network in 2018 and which focuses on gender equality, non-discrimination, and respect for fundamental rights and sexual and reproductive rights, which are especially threatened and violated in the case of women with mental health difficulties.

SHINE (Ireland)

A new Strategic Plan, **Making Change Happen**, for 2019 to 2021 was published in November 2018. This plan sets out a new innovative direction for the organisation, including the development of a more coherent family advocacy initiative, a research function and a communications strategy.



In 2019, Shine was immensely proud to celebrate their 40th anniversary. Since their establishment as a national organisation in 1979, Shine has worked tirelessly to shape better policies and services for all those affected by mental ill health. Shine has supported the rights of individuals and groups to enhance their recovery. Shine has promoted access to services, challenged negative attitudes and behaviours and delivered a variety of programmes and services.

An official celebration was held in October attended by people who use Shine services, family members and relatives, board, staff and volunteers, colleagues

from the mental health sector and friends of Shine. As part of the celebrations, Shine also developed an online video series "Shine People" celebrating and acknowledging the lives of those living with mental illness.

Quote from the video (individual who uses Shine services) :

"Shine is a place of refuge from the world. A place where you can get well.

Doing meaningful activities, where peer support happens. It is a life-saving place of hope when you are in despair. You learn things about yourself and eventually take wings to 'fly' again."

VASK (Switzerland)

In 2019, VASK reports a very positive message with a well established Board and having completed an extensive public relations programme. Urs Würsch, Vice President, was elected to the EUFAMI Board of Directors at the 2019 AGM. Due to the efforts of Urs, VASK is now actively participating in European affairs. It is interesting to learn how other countries deal with people suffering from mental ill health and their families.



VASK was invited to the "Club", a talkshow of the Swiss TV channel SF1. Bruno Facci, VASK's President participated (pictured far right). Other invited guests were: Andres Andrekson - alias Stress - Swiss musician; Patricia Veluscek, actress, who has lived for decades suffering from depression; Yvik Adler, psychologist and psychotherapist in Solothurn and Co-President of the Federation of Swiss Psychologists; Erich Seifritz, psychiatrist and director of psychiatric university hospital Zurich (PUK) and Karin Jann, psychiatric nurse and laughter yoga teacher. The show was broadcast on 26th November 2019 at 10.25 p.m. It can be viewed using the following link.

<https://medien.srf.ch/-/club-volkskrankheit-depressionen>.

VASK's new brochure in friendly colours is very appealing; in fact so popular, that a reprint was required. It can be found on their website

<https://www.vask.ch/de/Informationen/Broschuere>.

EUFAMI STRATEGY 2019-2021

EUFAMI is the European Federation of Associations of Families of People with Mental Illness, a democratic, non-profit organisation with an ongoing commitment to improving care and welfare for people affected by mental ill health.

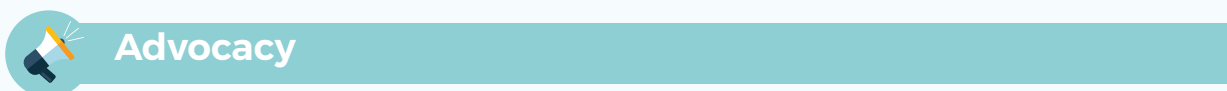
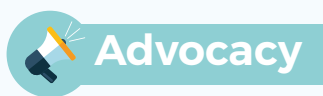
Mission

To be 'the voice' at European level of family members of people affected by severe mental illness.

Vision

That every person affected by mental illness and their family members receives the understanding and support they need without exclusion or discrimination so that their rights are recognised and protected.

Our Strategic Pillars



EUFAMI will be the voice at European level of families affected by mental ill health by:

- (i) Strengthening advocacy work and networks through specific projects which create capacity at membership and Secretariat level.
- (ii) Building closer networks and collaborations with other European institutions and international mental health organisations, and organisations such as the World Health Organisation (WHO) and the Organisation for Economic Co-operation and Development (OECD).

- (iii) Enhancing EUFAMI communications by using online and print media and to assist, where appropriate and feasible, in the translation of selected documents to support advocacy at a national level.
- (iv) Leading the fight against stigma, and promoting inclusion, by taking a multichannel approach to increase external communication, and emphasising the importance of safeguarding the human rights of people affected by mental ill health in line with the Convention on the Rights of Persons with Disabilities (CRPD).

Membership

EUFAMI will connect and support EUFAMI membership more effectively by:

- (i) Supporting and enhancing two-way communication with its members.
- (ii) Increasing the number of member organisations and strengthening co-operation with existing members.
- (iii) Encouraging and supporting the establishment of new family associations and strengthen those already in existence.
- (iv) Engaging in projects that include member associations, particularly those focusing on capacity building.
- (v) Developing and growing by strengthening and diversifying its financial and human resources, and working more closely with likeminded organisations and other partners, to become an alliance-based organisation.

Research

EUFAMI will ensure the voice of families is heard in research by:

- (i) Supporting and promoting family-focused research and collaboration with relevant stakeholders, including EUFAMI members, and actively following relevant research projects of other organisations.
- (ii) Using the most beneficial methods determined through research to support family members.
- (iii) Sharing research outcomes with member organisations, the media, and the wider public.

Find out more: www.eufami.org

2019 EUFAMI FAMILY CONGRESS



The following is a brief summary of the event. A more detailed description of the proceedings can be viewed at <http://eufami.org/eu2019fi/>

On the 19th and 20th September 2019, under the auspices of the Finnish Presidency

of the EU, and co-hosted by its Finnish member association FinFami, EUFAMI held its 7th European Family Congress in Helsinki, Finland.

The Congress consisted of a series of keynote speeches from representatives of family carers, users and professionals. A broad range of interactive workshops also took place at the Congress covering a wide range of topics which were of major interest to the delegates.

The theme of the Congress was “Families at the Heart of Europe – their role in the Economy of well-being” and approximately 100 participants attended the meeting.

Day One

OPENING

EUFAMI President, Miia Männikkö, opened the 7th Family congress by welcoming all participants. In her introductory remarks she put the focus on the need for families to be at the centre of attention in respect to healthcare family, a principle upon

which all of EUFAMI’s advocacy, membership, outreach and research work is built on. She also called on increased funding on the national and EU levels for research projects concerned with families.

Pia Hytönen, FinFami CEO, added her words of welcome to those of EUFAMI President, saying it was a great pleasure to co-host Congress with EUFAMI. She specially welcomed the FinFami members who had registered in high numbers to attend the Congress. Ms Hytönen commented that the Congress would provide an opportunity for FinFami to highlight some of the work being done in Finland, in particular in terms of Prospect and Open Dialogue.

Commissioner Vytenis Andriukaitis, European Commissioner for Health and Food Safety, sent a video message which was played to the audience. Dr Andriukaitis said that families and family carers are the beating heart of Europe, supporting and caring for some of societies most vulnerable members. The Commissioner acknowledged that many families and family carers did not get the help they needed or deserved, and he understood the frustration and sense of helplessness felt by many. The Commissioner highlighted the importance of EUFAMI in giving a voice to the needs and frustrations and highlighted the impact of mental ill health on the

European Union, in particular the deaths by suicide.

Ms Sofia Virta, Member of Finnish Parliament, Green Parliamentary group, congratulated FinFami and EUFAMI on the organisation of the Family Congress. She indicated her knowledge of mental health and the role of families had come from her time working at FinFami.

PLENARY SESSION 1

This plenary session was on the topic of 'Mental Health – the changing landscape over the last 4 years'. Mr André Decraene, EUFAMI Board member, spoke of his experience as father of a son with mental ill health and noted how important it had been for him and his wife to receive the support of his national association (Similes) not only for the information they could provide but also for the fact that they could meet other families that were in the same situation.

The next speaker, Ms Aikaterini Nomidou, Secretary General of GAMIAN-EUROPE, presented the patient's perspective, and touched upon her personal experience of mental health. She outlined how mental health is perceived in Europe, and sketched the context for the landscape in which patients and families navigate, focusing specifically on empowerment and exclusion.

Dr Julian Beezhold, Secretary General of the European Psychiatric Association, presented the healthcare professional perspective on the changing landscape of mental health and used the concept of the triangle of care as main example.

The concluding speaker was Dr Brigitta Alakare who focused on mental health in Finland indicating that mental ill health was the main reason for early retirement. She also spoke about Open Dialogue, which integrates systemic family therapy and psychodynamic psychotherapy.

The first day ended with a showing of the video 'Breaking Depression'.





Day Two

The second day of the Congress started with a presentation by Ms Sirpa Pietikäinen, MEP, who spoke of the Health Commission and the current interest in digitalisation, indicating that progress has meant new healthcare equipment has resulted in many people being unable to use it; so she suggested patients and families work on the topic of accessibility. She recognised there were many and varied carer issues which need to be recognised and acknowledged.

Marianne Thyssen, European Commissioner for Employment, Social Affairs, skills and Labour Mobility sent a video message in which she encouraged families and family carers to support the recently signed Directive on carers' leave.

KEYNOTE SPEAKERS

Ms Emily Hewlett, Health Policy Analyst of the OECD started her presentation by saying that for OECD families and carers were a source of knowledge, information and insight and that the OECD decided to focus

on mental health because it affects everyone with the focus on early prevalence. She indicated that the OECD has found that there are significantly high costs for mental health and that reducing the burden of mental illness also means looking at the treatment gaps and supporting people to return to work or stay in work.

Ms Inger Nilsson, former EUFAMI President, gave an overview of her experience with mental health and the family's first encounter with psychiatry. She also outlined how she became involved in setting up a small organisation in Sweden which proposed to work within community-based services to find out what could be done to improve things for families in the future.

PLENARY SESSION 2

The subject of this was 'Mental Health - the contribution of Carers to the economy of well-being'.

Prof. David McDaid from the London School of Economics, presented the preliminary results of 'The Economic Case for Caring', a study based on a comprehensive survey which included several validated instruments, which looked at different dimensions of caregiving experience such as loneliness, quality of life, time spent caring, value of caring, carer use of health services, etc.

John Saunders, Director of Shine, presented the EUFAMI Board response and indicated that giving a value to caring is very important and that the findings of the study will lead to a more accurate understanding of what being a carer means in real terms and that it will help others understand the type and level of support which is needed. This will help the carer so that he/she can continue to care in a healthy way, and it

is important for governments so they can implement formal support structures and networks in a way which is most effective.

Dr Ella Amir, Executive Director, AMI, Québec, concluded this session saying that changes can only be brought about via the work of family associations like AMI Québec and EUFAMI which are at the forefront of calls for change. Her very comprehensive presentation covered many very relevant items for caregivers.

PLENARY SESSION 3

This session was on the subject of “Caring and Wellbeing in a digital age”. The first presentation was made by Ms Saila Rinne, Head of Policy Sector, European Commission DG Communications Networks, Content and Technology, who spoke of the digital transformation of health and care. She focused on cross-border healthcare, promotion of health and disease prevention, health system reforms, transition to new care models towards community care based and integrated care structures, improved personalised medicine and more effective health and social care systems through the use of health data.

The next presenter, Dr Gerard W. Dawson, CSO P1vital, Digital Technology in PRISM and PReDicT, focused on two EU projects, including PRISM (Psychiatric Ratings using Intermediate Stratified Markers) in which EUFAMI is a partner. He indicated that the general concept behind PRISM was providing quantitative biological measures to facilitate the discovery and development of new treatments for social and cognitive deficits in Alzheimer’s disease, schizophrenia and depression.

Mr Baden-Kristensen Co-founder & CEO of Brain+ spoke of Digital Therapeutics for disorders of the brain and of Brain+, which is a one-stop-shop for cognitive treatment, early disease detecting and prevention which has the goal of helping patients regain independence and ability to function in daily life with confidence.

The final speaker was Per Torell, EUFAMI Board Secretary, who shared his experience as a father of a son suffering from mental ill health, who has a Smartphone but uses it as little as possible (he doesn’t like it near his brain), and a daughter who uses apps because they help with work/life balance.

This plenary session was concluded by a discussion on the topic of digitalisation and the impact this was having on the life not only of families and family carers but also of patients and the public in general.

Workshop sessions

After Plenary sessions 1 and 2, on both days of the congress, a series of parallel workshops were held, four per day, organised by FinFami with EUFAMI members. The topics for the workshops were (1) Good practices in education and training for family members; (2) Caring, Participation and Inclusion; (3) Families in Recovery and (4) Child and Young Carers.

Social

The delegates enjoyed a tapas dinner at the hotel restaurant on the evening of the 19th. This was an opportunity for delegates to relax, meet old friends, and hopefully make new ones.

HELSINKI DECLARATION

Families and carers at the heart of Europe - their role in the economy of well being

'Well Being' is a phrase regularly used but very seldom analysed; however, it includes many positive components, such as feeling happy, staying healthy, being socially connected and included, maintaining a purpose in life and most importantly looking after one's mental health.

WELL BEING CAN BE CLASSIFIED UNDER FIVE MAJOR HEADINGS

- ★ Emotional well being
- ★ Physical well being
- ★ Social well being
- ★ Workplace well being
- ★ Societal well being

WELL BEING IS HUMAN RIGHT

The role of families and carers in the economy of well being is

1. To recognise what well being is in their life - in order to identify and discover their role
2. To find their [own well being](#) in a manner that will enable them to maintain self esteem and resilience - a sense of purpose and personal fulfilment
3. To actively participate in creating, changing and monitoring laws and regulations on mental health on both a national and European level
4. To build meaningful social connections to avoid loneliness and isolation
5. To maintain a healthy diet and lifestyle, which will lead to a more healthy physical and mental well being
6. To help to spread the advantages of Self advocacy
7. To adhere to a realistic and beneficial relationship with new technologies and social media
8. To establish which support services are available and how they can be accessed, especially at times of greatest need and crisis
9. To assist in the protection of persons affected by mental health problems in order to reduce the practice of involuntary admissions and treatment, which can at times result in human rights violations
10. To seek out and raise awareness of appropriate education in the field of mental health problems, drugs, recovery, prevention and wellbeing promotion
11. To help influence legislators and actively participate in the development of disability and anti-discrimination legislation in order to ensure that persons affected by mental health problems have the right to share in all opportunities, challenges and responsibility of everyday life as is the right of every citizen

Helsinki, 20th September 2019

PROJECTS

Economic Value of Caring:



This is a project which builds on our Caring-4Carers (C4C) 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 this aspect of care is 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.

In 2019, work on the Economic Value of Caring Project continued where 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). It is planned to share this compelling evidence with policy makers at both European and national levels in order to encourage investment in policies and services which support family/informal carers. The surveys were launched in the following pilot countries - United Kingdom, Ireland, France, Italy, Spain, Malta, Denmark and Canada and data collection continues. Preliminary results were presented during EUFAMI's Family Congress in Helsinki in September 2019. Final results are expected to be published in mid 2020.

More information can be found at <http://eufami.org/economic-case-survey/>

PECUNIA

PECUNIA (Pro-grammE in Costing, resource

use measurement and outcome valuation for Use in multi-sectoral National and International health economic evaluAtions) is a project which 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.

EUFAM is a member of the PECUNIA Advisory Board, and is represented by Spyros Zorbas

PROSPECT Plus



For many years it has been the hope of EUFAMI to be in a position to update the Prospect Training Programmes to bring them in line with current practices and changes. The Janssen EMEA Foundation expressed an interest in recognizing and supporting European family caregivers in Mental Health and their positive contribution to the ongoing long-term care of their relatives. As a result, EUFAMI successfully applied to this Foundation for funding to carry out this update exercise. The grant which was negotiated meant that it was possible to begin the process of updating the Family and Friends Training Programme. The updated programme is called Prospect Plus.

The main difference between the Prospect Training Programmes and other like programmes is the “peer to peer” element of training programmes. The Prospect Facilitators of the Family and Friends Training Programme are themselves family carers and they bring into the training process an inner understanding of the family carer experience. The training process provides

much-needed tools to enable family carer participants to gain confidence, improve their coping skills, regain control, and improve their quality of life. These tools and skills should be part of the support package available for all family carers.

Due to some internal changes, the project was somewhat delayed and on World Mental Health Day 2019 the partnership with the Janssen EMEA Foundation and Prospect Plus project was announced.

Since then members of EUFAMI who were active in providing the Prospect Training Programme in their national countries were invited to take part in the updating process which will bring the Prospect content and materials up to date and add innovative components. Online meetings and communication, the collecting of updating feedback and content, the planning for a Kick-Off Event all took place in the last few months of 2019. The project brings a positive feeling to all those involved and there are great expectations for 2020.

VALUE OF TREATMENT



Following the successful collaboration with the European Brain Council (EBC) on the first phase of the Value of Treatment (VoT) project for brain disorders in 2017, EUFAMI is now a partner in the follow up project; the main goal of this follow up project is to examine health gains and socio-economic

impacts resulting from best practice health-care interventions in comparison with current care or no treatment, and to join evidence to policy. The first meeting took place at the end 2019 and more work is planned to take place in 2020.

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, which runs over a number of years, 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 assess-

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

The kick-off meeting held in Brescia, Italy from 13th to 15th November 2017 was followed by an AGM in Duesseldorf in October 2018 with monthly teleconferences to discuss progress made so far. In 2019 the Annual meeting was held in Venice and the monthly teleconferences continued to take place. The project will enter its final year in 2020 when the findings will be published.

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 Düsseldorf in February.

<http://prism-project.eu>

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

OTHER

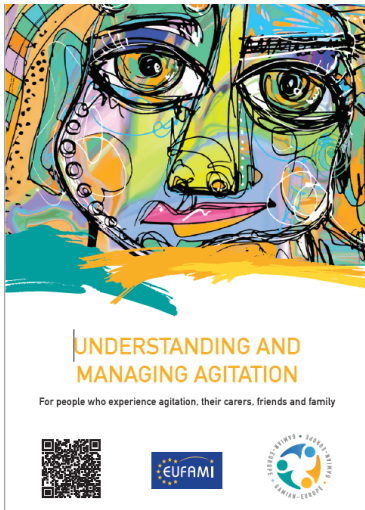
EUFAMI is a partner in some EU-funded projects such as Learn4Carers, Share4Carers and plays an active role in the dissemination of the project activities.

EUFAMI was also involved in the study on decisional capacity to explore patients, healthcare professionals and informal carers' views on the capacity of people with schizophrenia or bipolar disorder to make sound decisions about their healthcare and treatments. The data was gathered in 2019 and the results are expected to be published in the first half of 2020.

PUBLICATIONS

CARER Playbook

In 2019 EUFAMI finalised work on the Carer Playbook, which is a tool intended to provide guidance and advice to carers of those living with schizophrenia and to help them to navigate the struggles they may face. The tool was launched at the beginning of 2019 and has been translated into Czech, Lithuanian and Greek.



Agitation, a patient guide

EUFAMI, in collaboration with GAMIAN-Europe, has produced a practical guide on understanding and managing agitation. The guide was written by patients for patients, their families and caregivers with the aim of providing information about the experience of agitation, what leads to it, early signs, effective interventions and ways to empower patients and their families to manage agitation.

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

FINANCIAL REPORT

Audited Financial Results 2019

Balance sheet

Assets		2019	2018
	Fixed assets	0	183
Plant, machinery & equipment			183
Furniture			
Other tangible assets			
	Current assets	290.458	169.866
Trade debtors		5.384	13.082
Other amounts receivable		0	0
Cash at bank and in hand		283.842	154.133
Transitory accounts		1.232	2.651
Total assets		290.458	170.049
Liabilities		2019	2018
	Capital and reserves	59.865	56.618
Allocated funds		44.293	44.294
Profit carried forward		12.324	40.386
Profit of the year		3.248	
Loss of the year			28.062
Creditors			
Trade debts		40.996	14.109
Staff debts		10.544	9.322
Transitory accounts		179.053	90.000
Total liabilities		290.458	170.049

Income and Expenditure

Income €	2019	2018
Membership fees	11.725	12.575
EUFAMI Collaborating Partner Programme	50.000	65.000
Project funding	110.214	54.609
Recovered expenses/Honoraria/Other	7.888	8.291
Financial income	22	41
Own fundraising activities	0	7.000
Staff subsidy	717	1.426
Congress 2019	24.185	0
Total income	204.751	148.942
Expenditure €	2019	2018
Board of Directors	7.352	13.643
General Meeting	4.651	3.963
Staff Costs	51.129	76.730
Write off trade debtors	2.295	3.112
Office/insurances/suppliers	10.984	11.418
Annual report/Communications	1.624	3.589
Website/promotion/representation/IT Costs	4.915	6.752
Finance and legal expenses	14.572	15.244
Misc. costs including depreciations	814	1.304
Project expenses	84.777	41.249
Congress 2019	18.390	0
Total Expenditure	201.503	177.004
Profit/Loss	3.248	-28.062
Detail of Income		
1. Core (Collaborating Partner Programme)	2019	2018
Janssen	30.000	30.000
Lundbeck	0	25.000
Boehringer Ingelheim	20.000	10.000
Total	50.000	65.000
2. Projects	2019	2018
IMI PRISM project	0	620
EUFAMI-25	0	40
MENS	0	8.725
EU VIORMED	7.579	5.224
Economic Case for Carers	60.000	20.000
Carers Playbook	0	20.000
Prospect Plus	15.967	0
Capacity Project	7.000	0
Agitation Project	3.500	0
Value of Treatment	359	0
Shizophrenia Advisory Board	5.809	0
World Mental Health Day	10.000	0
Total	110.214	54.609

Audited Accounts Commentary

Income received by EUFAMI in 2019 to support our core and project operations amounted to €204,751, made up of a combination of funds from corporate donors through EUFAMI's Partner Programme, projects and membership fees.

Expenditure for 2019 amounted to €201,503 - the main items being staff and office costs, financial services and general overheads including Board Meetings and Project costs.

In my commentary for last year's Annual Report, I made reference to the fact that the Board was acutely aware of the financial position which EUFAMI was in and was making every effort to correct this situation. It is therefore somewhat heartening and on a positive note, I can report that we have completed the year 2019 with an excess of income over expenditure of €3,248.

In terms of income, and following the trend in recent past years, our Partner Programme income in 2019 reduced further and we received €50,000 from this initiative. When reading the accompanying financial details, it will become obvious that the majority of our funding for the year has come from two main projects - the 'Economic Case for Carers' project and the Prospect Plus project. Both of these are multiyear projects; in fact, initial results from the Economic Case project were presented at our Family Congress in Helsinki in September 2019.

I would just like to make reference to the Congress held in September 2019 and express our gratitude to FINFAMI, our Finnish member and Congress co-host, for their work and effort, which ensured that, apart from holding a very successful event, we can report a positive financial result.

While it is somewhat gratifying to be able to show a positive result, we still operate from year to year in a very unstable environment - which is nothing unusual or unexpected. We achieved the result partly due to the decision of our Executive Director to reduce working hours through the year and to depart from the role earlier than expected - the term was for two years.

However, the challenge, from a financial perspective, is to attain stability. Once again, I can assure all our member associations, supporters and friend that this matter remains high on its agenda.



Kevin Jones
EUFAMI Treasurer
May 2020

"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 2019 assembly took place in Helsinki, Finland on 19th September and elections were held for two Director positions. André Decraene from Similes Vlaanderen in Belgium and Urs Würsch from VASK in Switzerland were elected to the EUFAMI Board of Directors.

BOARD OF DIRECTORS

EUFAMI is governed by its Board of Directors and has met 3 times in person and held 5 teleconference meetings in 2019. 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.

In 2019 the Board of EUFAMI consisted of:



★ **MIIA MÄNNIKÖ,**
President,
FINFAMI,
Finland

★ **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



★ **FRIEDRICH LEIDINGER,**
Officer,
BApK,
Germany

★ **EDO BELAK,**
Officer,
SENT,
Slovenia



★ **URS WÜRSCH,**
Officer,
VASK,
Switzerland
(elected September 2019)

ACKNOWLEDGEMENT

In 2019, Martine Frager-Berlet from UNAFAM in France retired from the Board of Directors. She was member of the Board from 2011 until 2019 and held the position of Vice President from 2016 until end 2018.

We are most thankful to Martine for her valuable contributions to EUFAMI, both in her capacity of member of the Board of Directors, but – equally important – as a carer, representing EUFAMI on many occasions.

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
(until Oct. 2019)



GWEN CRAWFORD,
Project Officer
(Dec 2019 -)



EMELINE DUIJSENS,
Project Officer
(Jul. - Aug. 2019)



RITA GEERTS,
Administrator

EUFAMI MEMBERS

at 31 December 2019

STATS

38 members in 24 countries

in 22 of the 28-member countries of the EU

a federation of 31 family associations and 7 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](#) – Mielenterveysomaisten keskusliitto ry (Finland)

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

[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)

[MIND -YPSILON](#) (Netherlands)

[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 Associazione per la Salute Mentale (Italy)

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

Affiliated members

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

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

[Lélékben Otthon](#) – Közhasznú Alapítvány (Hungary)

[METIS Europe](#) (Belgium)

[MTÜ EPITÜ Lõuna-Eesti](#) (Estonia)

[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)



familien **selbsthilfe**
psychiatrie



EUFAMI STATS 2019



4 362
FANS

+11
NEW FANS



3 438
FOLLOWERS

+ 213
NEW
FOLLOWERS



2 673
NEWSLETTER
READERS



12
EU MEETINGS

6
PROJECT MEETINGS

11
EUFAMI MEETINGS