

Annual Report



2013



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EUFAMI's Funding Partners and Project Supporters - 2013

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We thank our Funding Partners and Project Supporters for their support in helping us to achieve our objectives.



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Introduction

On behalf of my fellow Board Directors at EUFAMI I am pleased to commend this year's Annual Report to all our friends and partners. I hope that readers will be uplifted to learn what we and our member associations across Europe have been doing over the past year to champion the cause of family members of persons affected by severe mental illness.

My own experience convinces me more than ever of the crucial need for EUFAMI's role at the centre of this whole movement. We are its strong advocate with influential people and with institutions where strategies are developed, policies shaped and decisions made. We show what can actually be achieved through voluntary co-operation and yet how so much more could and should be done given more resources. It is a great tribute to our member associations that they play such an inspirational part in response to growing demands for better mental health care services even at this time of continuing financial and economic pressures. We at EUFAMI exist to support their work in all ways we can.

Last year a staple contribution remained our personal participation at international and specialist congresses and conferences and our membership of relevant Advisory Boards, for example those sponsored by clinical and governmental agencies. That is where we can make sure that family needs and interests are powerfully registered and established. Details of the year's activities are in the Report.

In that connection our own special Family Conference held in Dublin in May stands out as a highlight. It was attended by the European Commissioner for health, Dr Tonio Borg, together with his senior officials, and by the Irish Minister for Health. A total of 190 delegates from 21 countries took part. At its conclusion we launched the Dublin Declaration, setting out a formal statement of rights for families of people with mental illness. To show its source more clearly we have renamed this "the EUFAMI Charter of rights of families and carers of people with mental illness" and we believe it should have lasting value. It is reproduced here.

Among other significant events the Board attended a special Prospect conference hosted by FinFami, our Finnish member association in late November. A particularly valuable outcome has been the development of five additional Prospect modules which will be released in 2021 as Prospect Plus.

As with any widely dispersed organisation of our size and scope we must go on working on our communications both between EUFAMI and its members and, not less, encouraging links between associations themselves. The further development of our engagement with social media and the promotion of meetings of clusters of members from different countries remain prominent. I would also commend the 20 year one page histogram as a simple and attractive summary of our story so far which can be used in many different settings.

As we look ahead, I see two specific ways in which we can further strengthen our position as EUFAMI. One is to expand our presence in Central and Eastern Europe by securing new members where the need for the support we offer is great. The other is to go on enlarging and deepening our relationships, at both the professional and personal levels, with other international and specifically European bodies concerned with mental health. I am confident that we can make headway with both of these.

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

Bert Johnson

EUFAMI President



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Associazione per la Rifoma dell' Assistenza Psichiatrica – ARAP (Italy)

ARAP (Association for the Reform of Psychiatric Assistance) was established thirty three years ago when the Italian law concerning treatment for mental health abolished psychiatric hospitals and even banned such wards in general hospitals. Consequently, care for patients with a mental illness is provided by the Mental Health Departments which have been established within the community. However, these departments are quite inadequate and, to date, patients still receive little or even no assistance.

Therefore, ARAP continues the battle for Reform and, in the meantime, endeavours to supplement, with the meagre means available, the lack of assistance for patients and families.

Below is a brief report of the main activities performed by ARAP during the year 2013 in pursuit of the above mentioned mission:

- Several petitions to amend the law concerning psychiatric treatment currently in force in Italy were submitted to the Italian Parliament's Health Committee.
- ARAP's regular call-centre service continued to operate in its offices.
- Having obtained the approval of families and/or carers, the project whereby expert psychologists perform follow-up visits for difficult patients was maintained.
- ARAP's regular Self-Help groups were held in the association's headquarters.
- ARAP continued to cooperate with other family associations, having the same purpose, located in Northern and Southern Italy.
- In cases when patients with a severe mental disorder have been denied treatment, the Head of ARAP's Legal Office and member of the association submitted various demands for care to the relative Mental Health Departments.
- Meetings were frequently held with various Mental Health Department officers.
- As a member, ARAP constantly attended the meetings of the Citizens' Councils for Mental Health.
- ARAP held meetings and interviews with the press and television on a regular basis.



Bundesverband der Angehörigen psychisch Kranker (BApK) – Familienselbsthilfe Psychiatrie (Germany)

Media coverage of mental illnesses has increased during the last number of years. The German Association of Carers – BApK - in cooperation with other self help organisations plans to contribute to the visibility of mental illnesses and the situation of the mentally ill in order to diminish social stigma. In 2013, BApK continued from 2012 the "Open Face" campaign with the purpose of increasing the exchange about the experiences of people with a mental illness with the broader public:

- Individual life stories should tell people more about what can help to find a self-confident approach to the public and the media

- BApK wants to encourage persons with a mental illness to become self-confident and well informed in dialogue with the media.

BApK started with interviews, wanting to know about the experiences of people with mental illness with stigmatisation and also wanting to find out about supporting factors which enable people with a mental illness to a self-confident response to such stigmatising experiences. BApK developed a questionnaire for the interviews and trained a number of carers and consumers for the interviews. This group of interviewers has started in different areas in Germany with the project. BApK's first conclusion is that it is still very difficult to talk about these experiences.



Confederación Española de Agrupaciones de Familiares y Personas con Enfermedad Mental - FEAFES (Spain)

FEAFES is the only organisation in Spain that has been bringing together, since 1983, all the federations and associations of people with mental illness and families. Nowadays FEAFES integrates almost 300 groupings with more than 45,000 members. Its mission is to improve the quality of life of people with mental illness and their families, to defend their rights and to represent the Associative Movement. To accomplish this mission, during 2013 FEAFES has developed a wide variety of activities. Amongst them, FEAFES would like to highlight the following activities:

FEAFES' campaigns focused on the visibilisation of people with mental illness and a positive attitude to mental health, with the aim of raising awareness in society. Some good examples of these campaigns are FEAFES' celebration of the World Mental Health Day in October, around the claim "Alternatives to the crisis. The value of our rights" and the development of the sensibilisation campaign "Queremos ser felices" ("We want to be happy"), that includes the launch of a specific website <http://www.queremosserfelices.org/>.

FEAFES has also developed several advocacy and lobbying actions during 2013, by taking part and establishing agreements with different national organisations in the field of mental health. Through these groups, FEAFES had the chance to make visible its concern about the national health reform, which may reduce the adherence of users to their treatment, to share its alternative proposal to the involuntary outpatient treatment and to show its strong disagreement with the recent cuts in national social and health services. Additionally, FEAFES has been especially active in the analysis on the Reform of the Spanish Penal Code and its impact on the rights of people with mental illness.

Finally, another activity to highlight is the celebration of the Seminar "European Meeting for Mental Health - Creating Synergies". It was an initiative of Mental Health Europe and organised by the five Spanish member organisations, including FEAFES. The meeting took place at the headquarters of FEAFES in Madrid during the morning of December 12th, 2012. About 35 people, mostly representatives of user associations, family and some professionals attended in order to discuss the possibility of creating a National Platform on Mental Health that could help to reach their common goals and have a unique voice when necessary.



FinFami – The National Organisation of Carers for the Mentally Ill (Finland)

FinFami's activities are based on the needs of members associations and family members. FinFami is both the national lobbying association for the family members of people with mental illness and the family work expert organisation. FinFami works as a central organisation for family associations. The values are humanity, transparency and co-operational competence.

FinFami has carried out three projects in 2013 – the Prospect project, which developed peer support group activities with member associations and in the public sector, a project which developed carer-oriented support methods for municipalities and a project which developed support methods for the children of mentally ill parents. FinFami, its activities, and the situation of family members were represented on many occasions. EUFAMI was and still remains FinFami's main partner in Europe.



HAFAL (Wales)

2013 was a milestone for HAFAL - Wales' principal charity for people with a serious mental illness and their carers: on 1st April HAFAL officially turned ten. What a decade it's been for them! The charity grew dramatically so that HAFAL now has a turnover of over £5 million and a staff of over 200. HAFAL's campaigning ensured that as well as the 1,200+ clients and carers they support each day, everybody in Wales receiving specialist services for mental illness now has the legal right to a holistic Care and Treatment Plan.

2013 (going into 2014) was no less groundbreaking. Service users and carers across Wales surpassed expectations yet again during the year's "Lights! Camera! ACTION!" campaign by recording some truly poignant, punchy and insightful film blogs about their recovery and the services they use. You can find these on HAFAL's Facebook page - please do have a look!

HAFAL also saw a number of exciting developments. They were awarded funding to develop a pioneering new Recovery Centre which will provide a progressive service user-led facility for people experiencing serious mental illness in need of in-patient care. Welsh Health Minister Mark Drakeford launched HAFAL's new Big Lottery-funded "Up 4 It" project which will deliver an Early Intervention Service for vulnerable young people experiencing psychosis. HAFAL also won a Care Programme Approach Association UK Award in the "Excellence in Providing Information about the Care Process for Service Users and/or Carers" category for its "How to get a great Care and Treatment Plan" training course – and HAFAL's new guide to Care and Treatment Planning reached an audience of 40,000.



Hafal sportsday

HAFAL's 2013 National Physical Health Awareness Day was a lot of fun, but the day also reinforced the message that improving physical health is key to recovery from mental illness. So in summer 2014 HAFAL will campaign with its partners to promote physical health for people with a serious mental illness and their carers. They will also campaign to ensure that direct treatments for mental illness, including both psychological therapies and medication, are up to scratch and promote patient choice.



Hilfe Für Angehörige psychisch Erkrankter - HPE (Austria)

Twice a year, counsellors from HPE Austria educate professionals who have a psychosocial background and who are specialised in occupational rehabilitation on how to include the relatives of their clients in their work. This happens in the form of a workshop.

When it comes to rehabilitation, relatives have a strong influence on the patients in general, particularly in terms of career. Anxiety and despair put pressure on the relatives, which in turn influences the constitution and state of self-confidence of the patient. Institutions are often confronted with these problems. In view of these circumstances, relatives need qualified information and guidance from professionals who are aware of their needs. In the course of this HPE training, professionals learn how to support relatives, so they can be supportive to the patients during their occupational rehabilitation. The Educational Institution of the Catholic Church in Austria invited AhA Salzburg (member of HPE Austria) to give lectures on „Mental Health in Families“ to achieve a higher level of awareness; herewith involving new target groups, which are close to the Catholic church. These lectures are held on request in several places in the county of Salzburg. The presentations are very well accepted and the discussions are promising.

The launch of a new psycho-social advisory board initiated by the government, in which AhA Salzburg is involved, took place in 2013. The aim of the board is to enact reforms in planning and organising comprehensive treatment and community based support for all people with severe mental illness.



HUMANA - Association for family members in care of people with mental disorders (Slovenia)

The Humana Association for family members (www.humana-svojci.si) was established in the year 2000 by family members, who carry the burden of caring for people who suffer from psychosis and concerns. It is the first and remains the only Slovenian humanitarian organisation of public importance primarily devoted to helping family members of people with problems of mental ill health. Humana has co-founded several national organisations in pursuit of better cooperation between several NGOs themselves, the public health and social services, professional staff and legislators. Humana's programme offers access to information, counselling, exchange of experience, maintenance and support of physical and mental health, as well as a continuous education on topics of mental health to family members and their affected loved ones. Humana is also publicly active in the field of prevention and destigmatisation.

In 2013 Humana organised 40 public events of education (professionally led lectures, an education in the understanding and management of stress, individualised educative meeting with a psychiatrist), 60 group meetings (self-help groups, exclusive group for family members, club for experience exchange), 15 events focused on the development of physical and mental health and numerous events of counselling in their office or via telephone (the Helpline is reachable 24 hours a day). Humana is sincerely grateful to the 2013 program co-financiers - FIHO, Ministry of Health of the Republic of Slovenia, City Municipality of Kranj, and the Municipality of Naklo.



KINAPSI – Athens Siblings (Greece)

The year 2013 was another active year for KINAPSI, the association of siblings of people with mental health problems in Greece (www.kinapsi.org). The association continued updating its members on mental issues by running workshops and seminars. They supported the operations of psychotherapeutic groups for siblings of people who suffer from mental health problems. For the first time, support was extended to its members in order to receive free individual counseling.

Monthly coffee meetings continued and offered support and advice to both members and friends. Additionally, through a series of various cultural events KINAPSI offered social alternatives and socialising opportunities for people with mental illness and their family members. KINAPSI members attended performances at the opera, the national theatre, various plays in collaboration with the Michael Cacoyiannis Foundation and museum guided tours free of charge (free



KINAPSI workshop

tickets were offered by collaborating parties).

In the summer of 2013, at St. Andrews' camp in Attica many of KINAPSI members combined their holidays with creative activities and sports; thanks to a fruitful liaison with the Municipality of Athens. Camp period lasted for 20 days (6-30 September) and daily activities included swimming, exercising, cycling, drawing and crafting.

Moreover, in the context of the European Month for the Brain on May 16th, 2013 at the Foundation of Biomedical Research of the Academy of Athens, the organising of the KINAPSI conference was a notable event. KINAPSI is also a partner in a research programme for Adult Attention Deficit Disorder with the body of Narodni institut pro deti a rodinu, as the coordinating partner and partners from Portugal, Cyprus and Sweden. The programme will be completed in November 2014 in Prague.



KI.PRO.DI.PS.A./A.G.M.I. – Advocacy Group for the Mentally Ill (Cyprus)

KI.PRO.DI.PS.A./A.G.M.I.'s core priority area of work is concentrated to seek and influence National and European policies about mental health and related issues for the interests of people



Angelic Voices Choir at World Mental Health Day Event

with mental illness and/or disabilities and that of their family and carers; towards decision makers whose decisions will affect their quality of treatment, psychosocial support consequently their quality of life, which are in line with Declarations etc. on mental health and human rights areas combating prejudice and promoting social inclusion and the promotion of mental health for the community in general.

These activities are directed to – relevant Authorities Bodies Service Providers, Media and Society, Stakeholders, such as, Ministries of Health, Social Affairs, Justice, Education, Social Welfare Department, Mental Health Services, Department of Social Inclusion and Disability (D.S.I.D.) Member of Parliaments, Local Authorities, Police, Press, Commissioner of Administration, Commissioner of Legislation, Mental Health Commission, National Confederation of the Disabled, Community etc. The axis of activities are directed and were implemented throughout different inputs with dissemination of information, interventions, views, positions, suggestions, etc in the areas and issues as follows:

De-Institutionalisation; Convention of Rights of People with Disabilities (C.R.P.D.); National Reform Programme (N.R.P.); Schemes, Services, Benefits, psychosocial /psychiatric Disability -Psychiatric Treatment Law of 1997, N. 77(I)/1997 - Barriers of integration and inclusion; National Health System Care and Mental

Health; Supporting policies for family carer's; Recognizing the particular difficulties of elderly parents and carers of people with mental health problems/psychiatric/psychosocial disability, stating respect for their daily struggle advocating for the improvement of services for their loved ones, for measures of relief for themselves as carers, removing barriers and creating opportunities for them for active aging. Promotion of Mental Health by A.G.M.I. is achieved between others through its membership status to European Organisations in participating as partner to their European projects, promoting messages recommendations etc. The variety of the community recipients stakeholders on various scales who within the contacts /cooperation are recipient of the messages of the A.G.M.I.



Landsforeningen for Pårørende innen Psykisk Helse -LPP (Norway)

In 2013, LPP elected a new board of directors. LPP also employed a new secretary general, established a new web-page, got a new register of its members, and in general got a new, fresh start. The focus has primarily been on strengthening the local organisations. In September the Norwegian parliament election was held and LPP have been an active part after the election, contacting members of parliament with the purpose of informing them of the field of families of people with mental illnesses, but also simply turning their focus on what the family organisation's needs are.

LPP experienced an increased level of acknowledgement among both governmental institutions, but also among other possible partners. The organisation is about to become a force to reckon with, and is included in an increasingly amount of projects and areas of interest. The organisation also experienced an increase in membership subscriptions with 12.5%, and is also now involved in multiple European cooperative projects. Overall, it has been an exciting year for LPP, with many changes and a lot of new possibilities and doors opening.



Landsforeningen SIND - Danish Association for Mental Health (Denmark)

In 2012 SIND held a Congress where new Articles of Association were adopted. According to these new Articles of Association, SIND has spent a lot of time and resources in 2013 to adapt the organisation to the new structure. The new structure will be fully implemented in 2014. During 2013 SIND continued to provide its comprehensive range of services to facilitate users and their relatives. Among these services the following are some examples - provision of information material for users and relatives (and everybody else who wants to know more about mental health topics), meeting and activity centres, education and training facilities (schools for service users). SIND is offering independent counselling for service users and relatives throughout the country. The counselling can be individual or in common interest groups. A professional psychotherapist normally heads the support groups, which may continue as self-help

groups. SIND is also maintaining a group of trained assessors who can assist service users during meetings with doctors, social service workers etc. SIND also maintains a network of service users and relatives who are trained to deliver lectures and participate in educational activities for mental health staff and other who need to learn from our experience. In 2013 SIND also further strengthened its work to influence political decision makers at local, regional and national level. In 2012 the Danish Government formed a mental health committee, which prepared recommendations for the future structure and development of psychiatric treatment in Denmark. SIND's President is one of the members of the committee, that finished its work in November 2013. Also in 2013 SIND conducted a campaign focusing on legal rights for users and relatives and continued to be very visible in the media.



Mental Health Association - MHA (Malta)

During 2013 Mental Health Association (Malta) core work was the development and strengthening of its partnership role with other local healthcare professionals and organisations that are committed to improve the quality of life of people with mental illness and their carers. To this end throughout 2013 MHA held seminars, talks and meetings with the various statutory agencies and NGOs working in healthcare and the social welfare field. During these events, MHA provided information in all forms about mental ill health and it highlighted the impact the illness has on both the patient and the family-carers.

MHA also actively participated in various public consultation seminars and workshops organised by the Ministry of Social Policy in preparation for the publishing of the Green Paper "A Framework for Poverty Reduction and for Social Inclusion". The correlation between mental health illness and poverty was highlighted. MHA was also represented in a workshop entitled "Working Towards the Implementation of the UNCRPD" in preparation for the Report issued by the National Commission Persons with Disability (KNPD) Malta.

Last year a Commissioner for Mental health and Older Persons was appointed. MHA lost no time in meeting the Commissioner to get his commitment and support especially for the ongoing campaign to mainstream acute mental healthcare into the general hospital in tandem with the development of an effective and accessible outreach community care. This is of utmost importance to promoting the improvement of service being provided as statistics recently released by the Minister of Health stated that only one fourth of patients at the local mental health hospital really need to be there.

During 2013 MHA in collaboration with another affiliated NGO has been providing support for family caregivers including family consultations, counselling, support groups and home-visits. The Empowerment course which is the flagship of MHA is in its 16th year running. It is very encouraging to see carers' enthusiasm for learning and to speak with a strong voice for their loved ones. Another book giving advice to family carers of persons with mental illness has progressed significantly in 2013 and it is hoped that by mid 2014 it is published. This book is being written in Maltese and is based on years of work and experience with relatives who regularly take care of a family member with mental health problems.

Finally last year, through the generosity of one of MHA's members the association now has its own place where members can

meet up and hold various activities. This should facilitate the workings of MHA in promoting the improvement of and advocacy for mental health throughout the life course.

New Choices (Russia)

New Choices took part in the creation of the video film “Leible” which tells about the life of people with different mental disabilities. This video can be viewed at http://www.youtube.com/watch?v=QZ4iRxx_6sc The film is provided with written English translation. In this film the name of the organisation is “New Opportunities”.



The National Forum of Families of People with Mental Illness - OZMA (Israel)

2013 brought improvements in mental health public services. OZMA played an important role to bring this about:

- 30 new ambulatory mental health clinics were opened by the public HMOs as part of the integration of somatic and mental health services under one roof.
- 10% increase in rehabilitations services budget. Special attention was given to the Orthodox and Arab communities in which self-stigma and neglect of mental health is high.
- OZMA took part in the national drive for healthy life-style (nutrition, physical activity, etc.) for the mental health patients and families.
- High level committee studying the future of mental health hospitalisation includes a representative from OZMA. The main goal is to boost the intensive mental healthcare units in the community and in general hospitals (“half way in” and “half way out”) as substitute to full hospitalisation in segregated mental health facilities. OZMA presented the mental health – NHS Trust in South West London and St George’s as a goal.

OZMA was instrumental in advancing mental health medications into the “public basket” including slow release injections.



OZMA promoting healthy lifestyle for MH patients and families

rethink
severe mental illness

Rethink Mental Illness (England)

Raising awareness of mental illness has been a key theme throughout 2013. Rethink launched the “Finding Mike” campaign in conjunction with Jonny Benjamin, who set out to find the man that saved him from committing suicide on Waterloo bridge six years ago. The campaign reached millions across the world and not only raised awareness about suicide, it raised Rethink’s profile, with their website alone receiving eight times the number of visitors and the campaign trending on Twitter in places as remote as South Africa.

The Schizophrenia Commission which launched in 2011 continued to go from strength to strength. It now has 12 NHS and independent mental health providers involved in Rethink’s Innovation network to share best practice and start implementing real changes that will improve people’s lives, including bridging the gap between physical and mental health care. As part of this great work Rethink launched its first Schizophrenia Awareness week in 2013 which is hoped to repeat year on year to keep schizophrenia at the top of the agenda.

Rethink has also been challenging stigma as part of the national anti stigma campaign “Time to Change”. The new campaign reached 15 million adults in England and Rethink launched its first young people’s pilot in the West Midlands and worked with teachers and young people in schools to raise awareness.

Rethink campaigned against the Work Capability Assessment led by a member with his own experiences of the unfair assessment of people with mental illness when it came to his son’s fitness for work. The campaign succeeded in changing practice. Rethink’s Lethal Discrimination report was published this year, revealing that over a third of the 100,000 ‘avoidable deaths’ in England every year are people with mental health problems.

Rethink has also been looking at new ways to increase their membership with a new dedicated members’ area of their website, as part of the wider improvements in order that more people can gain access to advice and information. Rethink continues to look for ways to involve people with direct experience of mental illness more in its work. In conjunction with the Service User Council Rethink created a new group’s strategy to make sure the groups across the country are really involved with the work and feel supported.

Finally Rethink has taken further steps to improve its work through the Rethink Information System allowing them to see better who is using its services and how these can best be supported; and by focussing on quality by bringing in a new quality programme known as PQASSO.



Shine - Supporting People affected by Mental Ill Health – Ireland

Throughout 2013, Shine continued to provide information, support and services to people affected by mental ill health as well as providing support to family members and carers of people with mental ill health in Ireland.

Shine officially launched its “Realising family friendly services campaign” in January 2013. A central activity of Shine is the support of family members affected by mental ill health. The objective of this campaign is to bring to the attention of all those involved, the importance of family involvement and inclusion in mental healthcare service delivery and to emphasise the need for mental healthcare service providers to have

a proactive and inclusive approach to dealing with families. Shine has identified a number of guidelines for realising a family friendly mental health service.

- Support for families
- Promotion of family/ supporter/chosen advocate involvement in the services user's care
- Provision of relevant information reflective of the family/supporter's needs
- Provision of crisis support
- Supports as part of the discharge process
- Involvement of family/supporter in the care planning process
- Family awareness training for mental health professionals

The ambition is to engage and discuss the issues with local mental health services with a view to acknowledging good practice and encouraging change in attitude and practice regarding the role of relatives and supporters as partners in care.

Shine continued the delivery of "Taking Control" workshops which are about practical ways of facing life's challenges, maintaining and taking control of your physical and mental wellbeing. These have been extremely successful to date.

In May 2013 Shine had the pleasure of co-hosting the EUFAMI conference at the Radisson Blu Hotel at Dublin Airport. The conference was officially opened by Ms Kathleen Lynch, Minister of State with responsibility for Mental Health. A large number of Shine delegates attended the conference and it was a great opportunity for members of various countries to meet and discuss the roles of families and carers.

Also in May 2013, See Change (Ireland's National Stigma reduction partnership co-ordinated by Shine) launched the Green Ribbon campaign. Just like the pink ribbon has become a powerful symbol for breast cancer awareness, this lime green ribbon has been established in the US and beyond as the international symbol for challenging the stigma of mental health problems. More than 150,000 green ribbons were distributed nationwide free of charge to spark a national conversation about mental health in boardrooms, break-rooms, chat rooms, clubhouses, arts venues, college campuses and around kitchen tables throughout Ireland. The aim is to make the month of May every year synonymous with promoting open conversation of mental health and challenging the stigma of mental health problems. For more information on See Change or the Green Ribbon campaign please visit seechange.ie and greenribbon.ie.



Similes Vlaanderen (Belgium)

On the 6th December 2011, Belgium was sentenced by the European Court of Human Rights (ECHR) and held responsible for the death by suicide of Tom De Clippel, a young psychotic adolescent who had been condemned for a minor offence and was sent into prison due to lack of space in a psychiatric hospital.

The situation of "internees", people with a mental ill-

ness who have committed minor infringements or criminal offences and who are therefore sent into custody among other regular prisoners, has been criticised and blamed for many years, not at least by the European Institutions. In February 2011 there were 4,093 "internees" in Belgium, among them 1,099 live in prisons, where they do not receive the psychiatric treatment they need and are entitled to. The tendency is increasing and, due to the fact that mental health services do not dispose of sufficient means to treat these people, it is expected that for the foreseeable future 24% of them will remain in regular prisons. Since family members of "internees" suffer from a double stigma, mental illness and a conviction for a criminal offence, Similes Vlaanderen set up a new family group: Similes, families of internees. The aim of this group is to organise activities, train and support family members of mentally ill people in prison. They also provide them with information about the legal rights and possibilities of their interned and mentally ill relative.

In October 2013, the Similes Federation launched a survey amongst volunteers. A questionnaire was published on their website in order to be answered by as many volunteers as possible, volunteers who are active in the nearly seventy small Similes associations throughout Flanders. The questions were various: e.g. questions about the different kind of activities the volunteers are organising in their association, questions about their motivation or lack of motivation, questions about what they need and expect from the Similes Federation, where or when they need to be supported and empowered etc.

Through this survey, Similes aimed at a better understanding of the needs of the volunteers in order to provide coaching and support, vital for the continuation of these volunteers' engagement.



SOPSI Athens (Greece)

In 2013, SOPSI continued the running of support groups for relatives of people with a mental illness. SOPSI's newsletter, MINIMATA, continued being published, despite all of the economic problems the association is facing. SOPSI also produced a 2014 edition of its annual calendar. On the 3rd March, SOPSI's Annual General Meeting took place and a new Board of Directors was elected.

Another activity was the opening of SOPSI's new sheltered apartment on 20th August 2013, with the contribution of National Strategic Reference Framework (NSRF). The apartment hosts four patients with mental health problems. At SOPSI's Day Centre several activities took place: Support group, psychological group, theatre group, current events group, social skills group, literature group, dance group, English lessons, nutrition seminars, community group, karaoke, cooking, cinema, excursions.

Also the board of directors took part in many seminars, conferences and sessions about mental health:

- 6th-9th March: participation of SOPSI in the national congress which had as title: "Crisis and Disaster". Several issues about mental health and the effect of economical crisis were discussed.
- 10th October: collaboration of SOPSI with **Hellenic Psychiatric Association** in the lecture with the opportunity of global day of mental health.
- 1st November: Participation in the lecture which took place in Aiginiteio Hospital, about precocious psychotic signs: intervention, structures and collaborations (lecture's title).

1992	1994	1995	1998	
<p>The birth of EUFAMI based on the principles of the De Haan Manifesto. The statutes were approved and signed by 17 associations from 10 European countries during a founding meeting in Overijse, Belgium</p> 	<p>Various surveys on needs of families and carers</p> 	<p>EUFAMI hosts its 1st European Congress in Barcelona</p> 	<p>EUFAMI member seminars</p> 	
1999	2000	2001	2002	2003
<p>A new communications window opens 'Working Together' is published</p> <p>EUFAMI's 2nd European Congress Stockholm</p> 	<p>The digital age arrives EUFAMI's website www.eufami.org</p> 	<p>Prospect EUFAMI's empowerment and training programme, rolls out in 14 countries</p> 	<p>Diamond Capacity Building programme for members</p> 	<p>EUFAMI's 3rd European Congress Colchester</p> <p>EUFAMI reaches out further with its electronic news-sheet @Bulletin</p> 
2004	2005	2006		
<p>EUFAMI's new home at Diestsevest in Leuven</p> 	<p>The release of the first set of Position Papers</p> <p>Pan-European ZeroStigma Campaign rolled out in 13 countries</p> <p>EUFAMI, the voice of the family, at the WHO European Health Ministerial Meeting in Helsinki</p> 	<p>EUFAMI and the EU EU Green Paper on Mental Health (full member consultation)</p> <p>GROW Development of Member Directory of projects</p> 		
2007	2008	2009		
<p>4th European Congress Toruń</p> <p>Toruń Declaration calling for the implementation of the Helsinki Action Plan</p> <p>STARS</p> <p>EUFAMI extends its capacity building support for its members</p> 	<p>EUFAMI continues to work on many European and Stakeholder Advisory Boards</p> 	<p>Pact on Mental Health and Well Being</p> <p>Focus on children major conference in Vilnius (The Forgotten Children)</p> <p>Vilnius Declaration on children with parents affected by mental illness</p> 		
2011	2012	2013		
<p>5th European Congress Basel</p> <p>The Basel Declaration on Community Care</p> 	<p>EUFAMI embraces the world of social media and networking YouTube, Facebook and Twitter</p> <p>Participation on the drafting of the WHO's Action plan for Mental Health</p> <p>Creation of Member Clusters</p> 	<p>EUFAMI reflects on 20 years of work with the Dublin Conference on the Role and Needs of Families</p> <p>Dublin Declaration on the rights of Families and Carers</p> 		

The following pages contain the EUFAMI Strategy for the years 2012 to 2015 inclusive, which was formally approved and adopted by the members of EUFAMI in 2012.

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 protected and promoted.

Vision

EUFAMI's vision is that people affected by mental illness and their families should be at all times afforded equal rights, entitlements and opportunities that are available to any other member of civil society and should be empowered to participate in the community in which they live.

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

Values

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

Systems of mental health care should be adequate to enable family members of people with mental illness to choose whether to be their carers or not.

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

The needs of carers themselves for support and understanding should be recognised and fully provided for.

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

Aims and Objectives

- To be recognised and involved as the leading European authority and advocate for families of people with mental illness
- 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 help member associations combine their efforts at regional and European levels and to reach out to more family associations
- To lobby European policy makers to support legislation providing mental health and social care services as a human right in each member state
- To campaign for adequate resources to be provided for these services for people with mental illness and their family carers
- To identify examples of good practice in the field of mental illness and communicate them appropriately throughout Europe
- To promote further research into the causes and management of mental illness and its treatment
- To 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 mental healthcare professionals and other organisations having similar purposes and objectives

Implementation Programme

EUFAMI's work over the period 2012-2015 will focus on the following seven areas

- Recognition of the role of the Family vis-à-vis care and treatment
- Empowerment of Families
- Representation – to represent the voice of families of persons with mental illness
- Capacity Building and Support for member associations across Europe
- Promotion of Best practice and Public Awareness
- Development of Partnerships
- Human Rights – to defend the human rights of people with mental illness and their families

Recognition of the role of the Family vis-à-vis care and treatment

It has always been a fundamental belief within EUFAMI that families can and should play a central role in the care and treatment of people with mental illness. EUFAMI has been working for many years to convince other parties that their role, together with their own expertise and special needs, should be fully acknowledged and provided for throughout Europe.

Conversely family members may not always wish to become carers of their ill relatives and therefore they should be afforded the right to make this choice without any adverse effect on the health or treatment of their ill relatives. EUFAMI is committed to uphold the right of family members to choose their life course.

Empowerment of Families

Empowerment is an important element by which people take control and action in order to overcome obstacles. It is about increasing the capacity of individuals to become more self-reliant and is a means which allows increased participation in decisions, along with increased dignity and respect and a sense of belonging and contributing to a wider community. Historically, people with mental health problems have not had a voice in the planning and implementation of mental services and support systems. Neither they nor their families have been involved in decision-making on mental health services. There is evidence that lack of influence or control can lead to poor health outcomes; conversely the ability to exercise control and influence can act as a protective factor against levels of disease risk. EUFAMI will do all in its power to correct this situation.

Representation – to commit as much effort as is necessary to represent the voice of families of persons with mental illness

EUFAMI, due to its widespread membership in geographic terms, is recognised as the credible voice of families in Europe and its priority is to advocate for families of people with mental illness. The needs of carers themselves for support and understanding should be recognised and fully provided for.

EUFAMI will strive to reach out to more family associations across Europe in order to raise the profile and situation of families affected by mental illness. EUFAMI will continue to campaign for adequate resources to be provided for services for people with mental illness and their family carers. It will also use all of its efforts to help its member associations with their efforts to gain more funding for mental health services and support, especially in the current challenging economic climate.

Capacity Building and Support for member associations across Europe

EUFAMI will help 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. It will assist member associations combine their efforts at regional and pan European levels and will reach out to involve more family associations.

EUFAMI will embrace as many family associations across Europe as is possible, especially in those countries where EUFAMI does not currently have membership.

Promotion of Best practice and Public Awareness

By using its wide range of networks and contacts, EUFAMI will strive to identify examples of good practice in the field of mental illness and communicate them appropriately throughout its own member network. Knowledge and examples of best practice benefits both persons with mental illness and their families. It will also use this information to strengthen its own position when it advocates with European legislators.

EUFAMI is committed to the dissemination of its consolidated information bank of knowledge and expertise to both its membership and other interested stakeholders in order to improve the living conditions of family members.

EUFAMI will campaign for changes in public attitudes so as to help remove stigma and discrimination against people with mental illness and their family carers.

EUFAMI will use its resources, to promote research into the causes and management of mental illness and its treatment.

Development of Partnerships

EUFAMI is committed to develop and strengthen partnerships between EUFAMI and mental healthcare professionals and other organisations having similar purposes and objectives. This commitment is driven by the belief that unity and partnerships lead to better outcomes for all people availing of mental health services.

True partnerships can only be formed when all parties understand the expectations of other parties and fully understand the worth of working together. This is especially more important at this challenging time when the current global economy is on a downwards spiral.

EUFAMI will continue to work with all stakeholders to ensure such partnerships.

Human Rights – to defend the human rights of people with mental illness and their families

All persons have the same human rights whatever their position, condition, status, gender, etc. It is the human right of all people with mental illness to share as fully as they can in the opportunities, enjoyments and responsibilities of everyday living.

EUFAMI will continue to work towards ensuring that the rights and interests of families of people with mental illness, including their own expertise and needs, are consistently represented and acknowledged at European level.

EUFAMI Internal Meetings 2013

During 2013 the Board of Directors met on four occasions - twice at the EUFAMI office in Leuven and also in Dublin and Helsinki. Additionally, a meeting between members of the Board and representatives of EUFAMI's Collaborating Partners took place on the 7th March via webex technology. During 2013, two Member Cluster meetings were arranged. The first one in 2013 was a meeting of the German speaking member associations of EUFAMI and this meeting took place in Munich in May. In September, a Cluster meeting of EUFAMI Belgian and Dutch member associations took place in Leuven. The Annual General Meeting of EUFAMI took place in Dublin on the 25th May 2103.

EUFAMI Collaborating Partner Meeting - 7th March 2013 (via Webex)

On the 7th March, EUFAMI held its first webex-enabled meeting when the Board held a meeting with EUFAMI's Collaborating Partners. From a technical view point, there were some 'teething' problems but this was only to be expected when using a new technology medium for the first time. After the formal introductions were completed, the Secretary General reported on the work which had been undertaken and completed by EUFAMI during the previous year, 2012. He then went on to outline the work programme planned by EUFAMI for the current year. This was followed by an open discussion between members of the Board and the representatives of EUFAMI's Collaborating Partners.

EUFAMI Board of Directors Meeting - 8th March 2013 - Leuven, Belgium

After the President opened the meeting and the minutes of the previous Board meeting were approved, the Treasurer presented the unaudited provisional results for 2012. The Secretary General provided a progress update on funding for 2013. Following financial matters, the Board discussed a number of membership related items - membership status, member communication and EUFAMI member cluster meetings. A cluster meeting of the German speaking member associations was planned to be held in Munich in the spring. A report was tabled in respect to activities related to EUFAMI's 20th Anniversary. The Board then reviewed recent and planned networking and representation activities and the updated calendar of events. After this item, the Secretary General provided a progress report on the work plan for 2013 and then the Board received updates on the ongoing review of current EUFAMI position papers. Finally, the Board spent some time preparing for the upcoming General Meeting which was scheduled to take place in May in Dublin.



EUFAMI Board of Directors Meeting

Meeting of the EUFAMI German speaking member associations - Munich, Germany - 15th May 2013

Representatives of EUFAMI's German speaking member associations - BApK, APAMP, VASK, HPE - and the Bavarian Family Organisation APK met with the President and Secretary General, representing EUFAMI, at a meeting which took place in Munich on the 15th May at the offices of APK. The meeting was a very open and lively one with contributions made from all of the delegates who attended. The agenda also reflected the fact that many matters of interest were discussed, including EUFAMI's strategy for 2012 - 2015, the work plan for 2013, new ideas for international networking - how to develop national projects into European/International projects, EUFAMI's financial plans (budget) for the next years and cross-national continuing training for volunteers.

EUFAMI Board of Directors Meeting - Dublin, Ireland - 23rd May 2013

The first item on the agenda of the meeting was the approval of the minutes of the previous Board meeting. This was followed by a detailed financial report from the Treasurer, assisted by the Secretary General, which included the presentation of the audited accounts for 2012, an update on the current financial position of EUFAMI as at the end of April and an update of funding for the current year, 2013. The Secretary General briefed the Board about the final arrangements for the major Conference which was due to take place the following day. He reported that there were 190 delegate registrations and provided details of the running order of the day including the arrival times of the Irish Minister for Mental Health and European Commissioner Dr Tonio Borg as well as the assignment of tasks at the conference for the Board members. The conference would be closed with the reading of the Dublin Declaration. The Board then spent time reviewing the arrangements for the General Meeting, due to take place in two days time. Other items which were in the agenda and which were discussed by the Board members were the 2013 calendar of events and networking and representation. The final item on the agenda was a report on the events related to EUFAMI's 20th Anniversary.

EUFAMI Annual General Meeting - Dublin, Ireland - 25th May 2013

The President opened the meeting, after registration of delegates was completed, by welcoming all of the delegates. The draft minutes of the EGM and GM in Leuven in May 2012 were reviewed and approved by the delegates as an accurate record of that meeting. The Treasurer presented the audited accounts for 2012 and reported that the year 2012 finished with an operational loss of €36,476 and explained the reason for this to be the fact that no major event

was organised in 2012, resulting in reduced amount of funding received. Also the EUFAMI balance sheet was reported to be in a healthy state at the end of 2012. The General meeting delegates approved the 2012 audited accounts by a show of hands. The delegates approved the re-appointment of the current auditors, VRC, and the accountants, De Kleine Prins, for the coming year and also approved a revision to the Budget for 2013 which had previously been approved by the General Meeting delegates. The proposed membership fees for 2014 were then adopted by the delegates as was the Annual Report for 2012. The meeting then dealt with a number of internal membership issues. A report on the activities related to the EUFAMI 20th Anniversary was presented to the delegates. The meeting then proceeded to review a set of revisions to the current EUFAMI position papers and these were agreed by a show of hands from the delegates. The work plan for 2013 was presented by the Secretary General and then the delegates were afforded time to provide feedback from the major conference which took place on the previous day. The overall impression was that the conference was well organised and very productive. The social dimension (conference dinner) was also found to have been very successful. Before the meeting was officially closed by the President, a number of delegates contributed to the final item on the agenda which was “members’ time for comment and feedback”.

Meeting of the Belgian and Dutch member associations of EUFAMI - Leuven, Belgium - 5th September 2013

On 5th September, a cluster meeting took place at the EUFAMI office in Leuven. Six associations were represented - Similes Vlaanderen, Similes Francophone, Similes Wallonie, Familieplatform Geestelijke Gezondheid (from Belgium) and Vereniging Ypsilon and Labyrint-in-Perspectief (from the Netherlands). EUFAMI was represented by its President, Treasurer, Secretary and the Secretary General. The agenda of the meeting included the current work plan and strategy of EUFAMI and how EUFAMI could support its members. A presentation on the Family Platform project was made by a representative from Similes Flanders. A discussion also took place on the current membership fees; also how European or non national activity/projects could be facilitated in a way which did not detract member associations from carrying out their national activities effectively.

EUFAMI Board of Directors Meeting - Leuven, Belgium - 6th September 2013

The President welcomed all and opened the meeting. The draft minutes of the May Board Meeting were reviewed and agreed. The Board also reviewed the draft minutes of the General Meeting and agreed that the draft minutes should be sent out to the General Meeting Delegates and member associations for review. The Treasurer presented the financial position as at the end of July 2013 and reported that EUFAMI appeared to be on target for a 'break-even' result in 2013. The Secretary General reported that all identified funding for 2013 had been secured by the end of July. Outstanding membership fees was a topic which the Board then discussed and requested that the Treasurer and Secretary General should meet and discuss the situation with a view to making a recommendations to the Board for proposed action. Under the item marked networking and representation, the Board noted receipt of a letter from the acting director at DG Sanco in which he welcomed EUFAMI's proposal to arrange a meeting between representatives from the Board and DG Sanco in order to exchange information about mutual plans and ideas. A report of the cluster meeting of Belgian member associations was then tabled and noted and some initial planning for 2014 cluster meetings took place. The Secretary General then provided a progress report on the 2013 work plan and on the planned activities related to the EUAFMI 20th Anniversary. This included a brief report on the conference along with the full delegate feedback in their meeting documents. The overall evaluation rating for the conference was one of satisfaction and success and the feedback received was very positive. From a financial aspect, the conference costs were fully covered by funding received. The Secretary General then proposed that

EUFAMI should prepare a toolkit, based on the Dublin Declaration, for members to use during the lead up to the EU elections next May. The Board agreed to this proposal. Following consultation with the President, the Secretary General had prepared a document which he tabled at the meeting, outlining some thoughts for the possible future direction and focus of EUFAMI with the intention to start a discussion on where or what EUFAMI should be focused for the coming 5 to 10 years. The Board spent some time examining and reviewing the contents and broad consensus was arrived at. This topic would continue for a number of future meetings. The Board also agreed with the Secretary General's proposal to set up an EU monitoring system as a service for the EUFAMI member associations. The calendar of upcoming events was reviewed as was the proposal to start work on two new position papers on the topics of “Early intervention in Psychosis” and “Talking Therapies”. Before the meeting closed, the members spent some time discussing feedback from an earlier brainstorming session undertaken by some of the Board members on alternative ways of funding.

EUFAMI Board of Directors Meeting - Helsinki, Finland - 30th November 2013

The President opened the meeting by welcoming all to Helsinki and expressing a special thanks to the members of FinFami for their kind hospitality to the Board. The minutes of the May Board Meeting were reviewed and agreed. The Treasurer provided a report on the current financial position of EUFAMI and a detailed discussion and review of the financial report ensued. He projected that a small excess of income over expenditure would be reported at year end. The Secretary General reported on progress with respect to income raising for 2014 and it was agreed that a EUFAMI partners' meeting should be organised in conjunction with the next Board Meeting scheduled to take place in March 2014. The Treasurer then tabled a proposal for an amended set of member fees for 2014 for consideration by the Board. The proposal, as tabled, was as a result of a review of member comments received and the situation of 2013 membership fees undertaken by the Treasurer and the Secretary General. A report was furnished in relation to findings to date on possible sources of alternative funding for EUFAMI. It was agreed that this exercise should continue. Under the agenda item networking and representation,

Board members and the Secretary General provided reports on various meetings and events which they attended in their capacity as representing EUFAMI. At this point in the meeting, Ritva Mantela from FinFami made a presentation to the Board members about extra modules which were developed for the Prospect Family and Friends Programme; five new modules were developed and added to what now is called "*Prospect PLUS*". The Secretary General presented a draft of the new EU Election toolkit for members and informed the meeting that the new EU monitoring service for members had been launched. The monitor is sent out to the EUFAMI member associations on a fortnightly basis. He then provided the Board members a progress update on work carried out to date in 2013 and elaborated on initial plans for 2014. Details were provided on the work carried out to date on the planned commemorative booklet and the internal mental health services survey. After the review of the events calendar was completed, the Board members reviewed the progress made to date on the two new planned position papers and agreed to aim to have them completed for presentation and approval at the General Meeting in 2014. The final item on the meeting agenda was a review of the current Board composition in respect to terms of office of the officers and future Board elections.

EUFAMI Representation

(some examples from 2013 where EUFAMI was represented at various conferences and external events by members of the Board and other EUFAMI members and staff; it is not a complete record due to space limitations)

January

On the 17th and 18th January, Bert Johnson, EUFAMI President, attended the 9th Workshop on Strategic Approaches to Health Policy organised by EGAN/Roche in Basel, Switzerland.

The Secretary General represented EUFAMI at the Expert Platform on Depression meeting held in Brussels on the 23rd January.

February

Terry Hammond, a member of Rethink Mental Illness (England) and a former EUFAMI General Meeting delegate along with the Secretary General took part in a Schizophrenia related training meeting of the Medical Affairs division of Takeda to speak about the family experience of living with Schizophrenia. The meeting took place in Zurich, Switzerland on the 6th February.

March

On the 4th March, the Secretary General attended an advisory board on schizophrenia meeting in Zurich and on the 5th and 6th, represented EUFAMI at the Annual International Experience Exchange for Patient Organizations, organised by Roche in Zurich.

Aikaterini (Katerina) Nomidou, SOFPSI n. Serron's delegate to the EUFAMI General Meeting represented EUFAMI at a conference titled 'Crises and Disasters - Psychosocial Consequences' organised by the World Federation on Mental Health, the Hellenic Psychiatric Association and the Society of Preventive Psychiatry. Katerina's presentation was titled - *The Burden of Care for families of persons with mental illness*. The conference took place in Athens, Greece from the 6th to the 9th March.



Aikaterini (Katerina) Nomidou represented EUFAMI at a Conference titled "Crises and Disasters - Psychosocial Consequences"

April

Bert Johnson, EUFAMI President, spoke at the European Psychiatric Association's 21st European Congress of Psychiatry - 'Europe Challenges the Burden of Mental Disorders' which took place from the 6th to the 9th April in Nice, France.

On the 23rd April, Nadine Fossion, EUFAMI Board Member and Secretary, represented EUFAMI at the Launch of a European White Paper on attention-deficit hyperactivity disorder (ADHD) in Brussels.

Alessandro Sveltini, another EUFAMI Board member, attended and spoke at the 6th Geneva Conference on Person Centred Medicine organised by the International College On Person Centred Medicine (ICPCM). The conference took place in Geneva, Switzerland from the 27th April to the 1st May.

May

The 2nd International Conference on Recovery, organised by a number of organisations including APAMP, a member association of EUFAMI, took place in Bolzano, Italy on the 9th and 10th May. Bert Johnson, EUFAMI President, and Alessandro Sveltini attended and spoke at the conference.

Bert Johnson, EUFAMI President, represented EUFAMI at the Annual General Meeting of the European Patients Forum in Dublin, Ireland on the 22nd April.

The European Parliament Special Interest Group on Mental Health and Wellbeing met in Brussels on the 29th May. The topic for the meeting was Mental Illness in the 21st century and the Secretary General was a participant at the meeting. On the following day, 30th May, he spoke at the conference on 'Mental Health and Young People' organised by the Public Policy Exchange group in Brussels. The topic of his presentation was *Supporting Families - early intervention and prevention*.

EUFAMI was represented at the Discussion of a policy document related to schizophrenia held in Vienna, Austria on the 31st May by Sigrid Steffen, EUFAMI past President.

June

On the 12th June, EUFAMI was represented by Martine Frager-Berlet, EUFAMI Board member, at the first IMI Patient Focus Meeting organised under the Innovative Medicines Initiative Joint undertaking (IMI/JY). The meeting took place in Brussels.

Filipa Palha, from ENCONTRAR+SE, EUFAMI's Portuguese member association, represented EUFAMI at the 21st World Congress of Social Psychiatry - Bio-Psycho Social model - The Future of Psychiatry held in Lisbon, Portugal from the 29th June to the 3rd July.

July

The Secretary General and Rita Geerts, EUFAMI office administrator attended a workshop on social media and web design organised by a number of advocacy groups, including EUFAMI. The workshop took place in Brussels on the 4th and 5th July and was supported by Janssen.

A further meeting of the European Parliament Special Interest Group on Mental Health and Wellbeing took place in Brussels on the 10th July and the Secretary General again participated.

September

Martine Frager-Berlet represented EUFAMI at the meeting of the EU Health Policy Forum which took place in Brussels on the 11th September. The meetings take place under the auspices of the EU Directorate General on Health and Consumer Affairs.

A meeting of the International Advisory Board on Schizophrenia took place in New York on the 12th September and EUFAMI was represented at this meeting by the Secretary General. There were also representatives from Australia, Japan, the US as well as Europe.

Catherine Bourke, a former General Meeting delegate from Shine (Ireland) and the Secretary General participated in a similar meeting to the one which took place earlier in the year (6th February) and at which Terry Hammond and the Secretary General participated. The meeting was held in Basel, Switzerland on the 18th September and was facilitated by Roche.

On the 21st September, Connie Magro, EUFAMI Vice President, attended and spoke at a Round table on mental health services in Greece organised by the Forum of Mental Health Professionals, Associations of Families for Mental Health and the Association of Users of Mental Health Services 'The Self-Representation'. Connie's presentation was titled 'Mental Health Policy – EUFAMI's experience from working at the European level'.



Connie Magro

October

On the 1st October, Nadine Fossion, EUFAMI Board member, attended the 'Depression in the Workplace' event in Brussels. The Secretary General participated at the European Health Forum in Gastein, Austria on the 3rd October. He spoke at the 'Schizophrenia and Social Inclusion - Perspectives, needs and solutions' session when he presented findings from the *Social Inclusion And Schizophrenia Global Survey* which had been ongoing for the previous six months.

The Secretary General also attended the 26th ECNP Congress which was held in Barcelona from the 5th to the 9th October and participated at the ECNP Collaborative Forum which took place during the Congress.

On the 7th October, Nadine Fossion attended the Workshop

and Debate on the 'Future of health R&D investment in Europe' which took place in Brussels. On the same day, John Saunders, EUFAMI Board member and Treasurer, represented EUFAMI at the 'mhGAP Forum' which was organised by the World Health Organization Europe office in Geneva, Switzerland.

On the 10th October, Bert Johnson, EUFAMI President, spoke at the opening ceremony of the Lithuanian EU Presidency Conference 'Mental Health: Challenges and Possibilities'. This conference was organised by the Ministry of Health and the Ministry of Foreign Affairs of Lithuania and was held in Vilnius, Lithuania.

A meeting of the EU Parliament Special Interest Group on Carers was held in Brussels on the 15th October and the Secretary General was one of the speakers at the event.

Finally in October, Begoñe Ariño, EUFAMI past President, represented EUFAMI at the 'International congress on employment of people with Mental Illness' which was organised by FEARP (Spanish WAPR branch) and held in Murcia, Spain on the 24th and 25th of the month.

November

A further meeting of the EU Parliament Special Interest Group was held in Brussels on the 5th November and Nadine Fossion represented EUFAMI. On the 12th November the Secretary General participated at the 4th Roundtable on Alcohol related illness in Brussels. This meeting was facilitated by Lundbeck.

Bert Johnson, EUFAMI President, attended the 30th Anniversary Symposium of the European Psychiatric Association which was titled 'Are people with Mental Illness truly citizens of Europe?' The symposium was held at the Council of Europe, Strasbourg, France on the 15th November.

On the 20th November the Secretary General attended the Expert Platform on Depression meeting in Brussels. On the 21st and 22nd November, the Secretary General participated at the meeting of the Governmental Experts on Mental Health which was held at the EU Commission's offices in Luxembourg.

The Secretary General also represented EUFAMI at the 2nd meeting of the ROAMER Advisory Board in Barcelona on the 26th November. ROAMER is a project funded under the Directorate General for Research's Seventh Framework programme.

Finally the full Board of EUFAMI attended a special Prospect conference hosted by FinFami, EUFAMI's Finnish member association, on the 29th November. A very positive outcome from this project is the development of 5 additional Prospect modules which will be released in 2014 as Prospect Plus.

December

On the 16th December the Secretary General attended the annual Gamian Awards night in Brussels, where Dr Matt Muijen from the WHO Europe office received the annual award in recognition of his efforts and contribution to the WHO's recently published Mental Health Strategy and Action |Plan for Europe. On the following day, he also attended the final meeting of 2013 of the EU Parliament Special Interest Group on Mental Health and Wellbeing.

EUFAMI European Family Conference - Dublin 24th May 2013

EUFAMI hosted a major European Family Conference in Dublin on Friday, 24th May 2013. It was co-hosted by Shine, EUFAMI's Irish member. The Conference was officially opened by Ms Kathleen Lynch, the Irish Minister of State with responsibility for Mental Health. Dr Tonio Borg, EU Commissioner for Health and Consumer Affairs also addressed the delegates, who numbered 190 from 21 European countries. This special Conference, under the patronage of his Excellency, Michael D Higgins, President of Ireland, was held to mark the 20th Anniversary of the founding of EUFAMI.

Dr Gráinne Fadden, Honorary Senior Research Fellow at the University of Birmingham and Director of the Meridian Family Programme gave a presentation on "Families and carers in Europe" and this was followed by a presentation from Dr Matt Muijen, Senior Policy Adviser, Mental Health WHO on "A new strategy for Europe". An interactive roundtable discussion took place with panellists discussing the role of families in mental health. This was facilitated by the "Entertrainer", Robert Carley. In the afternoon there were four breakout sessions based around four major themes – empowerment of families and carers, partnership in practice, education and quality information and the impact of caring on families and the health issues which they encounter.

The conference closed with the release of the Dublin Declaration which was unanimously endorsed by all delegates. The conference was a great opportunity for members of various countries to meet and discuss the roles of families and carers, make new friends and renew old acquaintances. Delegates attended a dinner reception on the evening of the conference and were entertained by Truly DiVine and her jazz band and Reel Style Irish dance troupe.

The Dublin Declaration (now renamed *The EUFAMI Charter of rights of families and carers of people with mental illness*)

EUFAMI's vision for the future for families

All families and persons affected by mental ill health should at all times be afforded equal rights, entitlements and opportunities that are available to any other member of civil society and should be empowered to participate in the community in which they live.

The role of families

- 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.
- Families should not be discriminated against or



Delegates and speakers at the Dublin Conference



European Commissioner for Health, Dr Tonio Borg

held responsible legally or financially for their family member directly affected by mental ill health. State mental health care should be adequate to enable family members of people with mental illness to make their choice without any feelings of personal guilt.

The needs of families

- The needs of families and carers themselves for support and understanding should be recognised and fully provided for by the state authorities. Families should have a right to the opportunity to state their emotional, practical and financial needs so that they can be empowered to acquire the necessary coping skills to fulfil their caring role.
- Families need to be cared for to ensure that their own physical and mental health is well maintained and supported. Evidence exists widely to show that this is not happening and that family member's health suffers. Depression amongst families is increasing and much is going un-diagnosed. Families should be provided with a statement of their own needs on a routine basis, with written records of these needs, and continuing assessment. Plans for meeting identified needs should be implemented and audited.
- The need for families and carers to recover from the experience and trauma of mental illness must be formally recognised and services provided to help them with their own recovery.

Public Authorities and statutory service providers

- Resources must be made available to meet those needs to enable family carers to carry out their role effectively. This may involve costs of training, counselling or other emotional help, providing information and financial help (for respite breaks, and travel costs to visit their relative)
- Such resources should be available to meet the family's needs, over time, in a planned way. They may include factual information, training in new skills (identifying signs of relapse, communication and problem-solving skills), support for themselves, e.g. counselling, advocacy, and support for self-help carer groups, help lines, peer support (carer to carer), respite, or help with identifying their role.
- Legislators and statutory service providers must be proactive in providing evidence-based family intervention services. They should not leave this to voluntary groups. The evidence for family interventions has been available now for thirty years, and it is negligent that these approaches are not yet widely available.

- The development of Comprehensive Community based services is seen as both essential and desirable if recovery is to be a realistic possibility. However, it is imperative that mental health care services provide the services outlined above to family members so that they can carry out frontline care, which is essential as a consequence of community care, more effectively. The sharing of information on the wellbeing of the person affected by mental ill health is essential.

* The Dublin Declaration was unanimously endorsed by all delegates attending EUFAMI's special European Family Conference held in Dublin, Ireland on Friday, 24th May 2013 to mark the 20th Anniversary of the founding of EUFAMI under the patronage of his Excellency, Michael D Higgins, President of Ireland. The Conference was officially opened by Ms Kathleen Lynch, Minister of State with responsibility for Mental Health. Dr Tonio Borg, EU Commissioner for Health and Consumer Affairs also addressed the delegates, who numbered 190 from 21 European countries.

Finnish Prospect Seminar



Bert Johnson delivering opening address at FinFami's Prospect Seminar

FinFami, EUFAMI's Finnish member association, held a Prospect Conference on the 29th November in Helsinki, Finland at which over 50 delegates attended as well as the full Board of EUFAMI. It was the closing seminar of FINFAMI's two year project based on Prospect, EUFAMI's peer to peer empowerment and training programme, and the title of the seminar was 'The Power of Peer Support'. There are Prospect groups for family and friends / carers in 14 member associations of FinFami and groups are organised in 20 municipalities. There are now 59 certified facilitators in the Finnish Prospect family and friends training programme and 9 instructors who can organise training programmes to

recruit and train more facilitators. There have been about 250 participants in these Prospect groups.

The seminar consisted of a number of presentations including the results of a wellbeing survey which was conducted during the project. The Chairwoman of FinFami, Anita Ruutiainen, officially opened the seminar and Bert Johnson replied on behalf of EUFAMI. Aila Paloniemi, a member of the Finnish parliament and Chairwoman of Young People's Mental Health also spoke. Eija Stengård, a leading Finnish Psychologist made a presentation titled 'A meaningful life- mental health is strengthened through everyday action'. Eija has long been associated with EUFAMI. Vaula Ollonen, the Prospect-coordinator at FinFami presented the results of the wellbeing survey 'The effect of Prospect groups on the wellbeing of family members'.

A very positive outcome from this project is the development of 5 additional Prospect modules which will be released in 2014 as Prospect Plus. This has been warmly welcomed by EUFAMI. The seminar finished with the official acknowledgement of the Finnish Facilitators and those involved in the development of Prospect Plus.



EUFAMI core and project related expenditures - 2013

Income €	2013	2012
Membership fees	€ 28.900	€ 21.475
Prospect fees	€ 0	€ 2.083
EUFAMI Collaborating Partner Programme	€ 130.000	€ 90.000
Project funding	€ 124.829	€ 8.000
Recovered expenses/Honoraria/Other	€ 17.717	€ 11.761
Financial income	€ 1.360	€ 1.532
Extraordinary income	€ 117	€ 328
Total income	€ 302.923	€ 135.179
Expenditure €	2013	2012
Executive Committee	€ 0	€ 15.772
Board of Directors/General Meeting	€ 20.913	€ 6.455
Prospect costs	€ 0	€ 271
Staff Costs	€ 117.650	€ 108.252
Write off trade debtors	€ 2.359	€ 3.175
Office accommodation/insurance/suppliers	€ 10.563	€ 16.960
Annual report/Communications	€ 2.675	€ 2.727
Web site/promotion	€ 429	€ 532
Finance and legal expenses	€ 15.139	€ 14.758
Depreciations	€ 312	€ 523
Expenses projects	€ 121.733	€ 0
Financial charges	€ 8.697	€ 2.229
Total Expenditure	€ 300.469	€ 171.655
Profit/Loss	€ 2.454	-€ 36.476

Detail of Income

1. Core		2013	2012
Janssen	EUFAMI Collaborating Partner Programme	€ 30.000	€ 40.000
Lilly	EUFAMI Collaborating Partner Programme	€ 25.000	€ 25.000
Lundbeck	EUFAMI Collaborating Partner Programme	€ 25.000	€ 25.000
Hoffmann - La Roche AG	EUFAMI Collaborating Partner Programme	€ 25.000	€ 0
Takeda	EUFAMI Collaborating Partner Programme	€ 25.000	€ 0
Total		€ 130.000	€ 90.000
2. Projects		2013	2012
Hoffmann - La Roche AG	Miscellaneous	€ 0	€ 8.000
Hoffmann - La Roche AG	Family Survey	€ 8.000	€ 0
Hoffmann - La Roche AG	Healios	€ 20.202	€ 0
Delegate Fees	Dublin Conference	€ 9.552	€ 0
Hoffmann - La Roche AG	Oxford University Schizophrenia Project	€ 87.074	€ 0
Total		€ 124.829	€ 8.000
3. Other Support		2013	2012
Takeda	Honoraria for Training Day	€ 2.000	€ 0
Takeda	Giving Tree initiative at ECNP congress	€ 3.000	€ 0
Total		€ 5.000	€ 0

Balance sheet

Assets	2013	2012
Fixed assets	€ 127	€ 439
Plant, machinery & equipment	€ 0	€ 200
Furniture	€ 127	€ 239
Other tangible assets		
Current assets	€ 389.741	€ 440.079
Trade debtors	€ 34.335	€ 2533
Other amounts receivable		
Current investments		
Cash at bank and in hand	€ 353.335	€ 430.907
Transitory accounts	€ 2.071	€ 6.640
Total assets	€ 389.867	€ 440.517

Liabilities	2013	2012
Capital and reserves	€ 165.715	€ 163.260
Allocated funds	€ 44.293	€ 44.293
Profit carried forward	€ 121.421	€ 118.967
Profit of the year	2.454	
Loss of the year		€ 36.476
Creditors	€ 224.153	€ 277.257
Trade Debts	€ 11.832	€ 7.377
Staff debts	€ 5.626	€ 5.260
Transitory accounts	€ 206.695	€ 264.620
Total assets	€ 389.867	€ 440.517

Audited Financial Results for 2013 - Commentary

Income

The funding which EUFAMI received for support of its core operations under the EUFAMI Collaborating Partner Programme in 2013 amounted to €130,000, which was an improvement of €40,000 from the 2012 figure of €90,000. This increase in Partner income can be attributed to the successful efforts to recruit new partners. In 2013, two new organisations joined the EUFAMI Collaborating Partner Programme, Hoffmann-La Roche and Takeda - a very welcome development. EUFAMI wishes to acknowledge the support which it received in 2013 from its existing and new partners. With respect to project related income, again I am happy to report an improvement - an increase of €116,829 from €8,000 in 2012 to €124,829 in 2013. The main project income was received from Hoffmann-La Roche to fund a schizophrenia related project with Oxford University Hospital. The amount which is being recognised as revenue for 2013 is a portion of the cash which EUFAMI received in later 2012 and which was reported on the Balance Sheet for 2012 - the remaining unexpended amount remains on the Balance Sheet and will be recognised as revenue in 2014 when the project is completed. Other project funding received was in respect to the Dublin Conference and a small piece of work carried out by Healios (an organisation providing carer support using web and telephone technologies). All other lines of income in 2013 were as expected.

Expenditure

Staff related costs increased in 2013 due to normal wage increases and extra expenses incurred in day to day representation and attendances at meetings and conferences; but much of the expenses was recovered and is reflected in the income side under Recovered Expenses and Honoraria. When reading Board related costs, one needs to consider a combination of Board and Executive Committee costs for 2012; this is due to the changeover in 2012 as a result of the amendments to the statutes covering governance. From 2013, we will only be reporting Board costs. For a second year running, of-



John Saunders

office costs again dropped from €16,960 in 2012 to €10,563. Overall our core operations expenditure was down by approximately €5,000 on budget.

In respect to projects, two payments have been paid to date as per our agreement with Oxford University Hospital for the schizophrenia project. The outstanding funding, which is reflected in the Balance Sheet will be paid out in 2014 on successful completion of the project. Our major Family Conference, held in Dublin in May 2013, was successfully fully funded with a minor income excess of €2,228. The Healios project was a once off minor project although it could be possible that we may have some further engagement with Healios in 2014.

Overall Comment

Through a combination of a proactive management Partner programme and prudent control of costs, we have managed to turn around a deficit of €36,476 reported in 2012 to a small profit of approximately €2,454 in 2013. Our member associations and supporters should welcome this development and recognise the positive message it conveys in respect to how EUFAMI carries out its work and responsibly carries out good management of its resources, however limited they may be.

However, we must never become complacent and must be at all times vigilant and proactive in terms of attempting to seek out new sources of funding. Like all other European NGOs, this requires quite an amount of time and effort. Once again, we completed the year without having to reduce our reserves at any time during the year.

Also the EUFAMI balance sheet overall is in a healthy state at the end of 2013. Cash at Bank at the end of December 2013 amounts to €353,335 which is a combination of our reserves and current ongoing project funding. I would like to express my thanks both to the staff at EUFAMI and our accountants, De Kleine Prins, for their work throughout the year and their assistance all round.

John Saunders





Treasurer

AEIPS		Portugal	Associação Para o Estudo e Integração Psicossocial Av. Antonia Jose de Almeida 26 , P-1000 043, Lisboa - Tel. +351 21 845 35 80 aeips@mail.telepac.pt - www.aeips.pt
APAMP		Italy	Associazione Parenti ed Amici di Malati Psicici Via G. Galilei 4/a, I-39100 Bolzano - Tel. +39 0471 260 303 info@auto-aiuto.it - www.selbsthilfe.it - www.auto-aiuto.it
ARAP		Italy	Associazione per la Riforma dell' Assistenza Psichiatrica Via Nomentana 91, I-00161 Roma - Tel. +39 06 855 38 04 arap@arap.it - www.arap.it
BApK		Germany	Bundesverband der Angehörigen psychisch Kranker Oppelner Str. 130, D-53119 Bonn - Tel. +49 228 63 26 46 bapk@psychiatrie.de - www.psychiatrie.de/bapk/
Bedre Psykiatri		Denmark	Landforeningen Pårørende til Sindslidende Livjærgade 20, DK-2100 København - Tel. +45 35 25 46 00 info@bedrepsykiatri.dk - www.bedrepsykiatri.dk
FEAFES		Spain	Confederación Española de Agrupaciones de Familiares y Personas con Enfermedad Mental Calle Hernandez Mas, 20-24, E-28053 Madrid - Tel. +34 915079248 calidad@feafes.com - www.feafes.com
FEDEAFES		Spain	Federación de Euskadi de Asociaciones de Familiares y Enfermos Psíquicos Tres Cruces 5 Bajo, E-01400, Llodio Alava - Tel. +34 94 4069430 fedefes@yahoo.es - www.fedeafes.org
FINFAMI		Finland	Omaisiet Mielenterveystyön Tukena Keskusliitto Ry Meritullinkatu 4 B 10, FIN-00170 Helsinki - Tel. +358 9 726 1180 keskusliitto@omaisten.org - www.omaisten.org
HAFAL		UK Wales	Suite C2, William Knox House, Britannic Way, Llandarcy, GB-Neath SA10 6EL Tel. +44 1792 81 66 00 - hafal@hafal.org - www.hafal.org
HPE		Austria	Hilfe für Angehörige Psychisch Erkrankter Bernardgasse 36/14, A-1070 Wien - Tel. +43 1 526 42 02 office@hpe.at - www.hpe.at
HUMANA		Slovenia	Združenje Svojcev pri Skrbi za Mentalno Zdravje Oldhamska 14, SLO-4000, Kranj - Tel. +386 4 2011720 humanakr@volja.net - www.humana.grozd.eu
KIN.A.PS.I		Greece	the Movement of Siblings of Persons with Mental Problems Naxou 19, GR - 152-35 Chalandri (Athens) – Tel. +306946003522 kinapsi@gmail.com - www.kinapsi.gr
KIPRO.DI.PS.A		Cyprus	Advocacy Group for the Mentally Ill Phidiou 12, Larnaca 6011 - Tel. +357 99 64 88 50 agftmi@cytanet.com.cy
LPP		Norway	Landsforeningen for Pårørende innen Psykiatri Brugata 1, N-0186 Oslo - Tel. +47 21 07 54 33, Fax: No longer in use lpp@lpp.no - www.lpp.no
LSPŽGB		Lithuania	Lietuvos Sutrikusios Psichikos Žmonių Globos Bendrija Kaštonų str. 4, LT - 01107 Vilnius - Tel. +370 5 262 8936 lspzgb@takas.lt - www.lspzgb.lt
MHA		Malta	Mental Health Association "Chamonix" 88, Brgihella Street, Birkirkara BKR 1868, Malta Tel. +356 21 43 56 41 - assistance@mhamalta.com - www.mhamalta.com
New Choices		Russia	Общероссийская общественная организация инвалидов "Новые возможности" 3 Poteshnaya Str, RUS-107076 Moscow - Tel. +7 095 963 14 35 levinan36@gmail.com - www.nvm.org.ru
OZARA		Slovenia	Nacionalno združenje za kakovost življenja Ljubljanska ulica 9, SL-2000 Maribor Tel. +386 2 33 00 444 - Fax 02 33 00 447 info@ozara.org - www.ozara.org
OZMA		Israel	the National Forum of Families of People with Mental Illness Box 1154, IL-53311 Givataim, Israel Tel. + 972 2 6585437 - Fax + 972 2 6585261 ozma.office@gmail.com - www.ozma.org.il
POSOPSI		Greece	Panellinia omospondia Syllogon oikogeneion Gia Thn psychiki Ygeia 236, Eleftheriou Venizelou Str. - GR-163 41 Ilioupoli Athens Tel. +30 210 994 80 98 - posopsi@gmail.com - www.posopsi.org
PSICHE Lombardia		Italy	via Anfiteatro 14, 1-20121 Milano Tel. +39 02 805 24 78 psichelombardia@yahoo.it - www.associazioni.milano.it/psiche
RETHINK		UK England	Mental Illness 15 th Floor 89 Albert Embankment, GB - London SE1 7TP Tel. +44 207 330 9145 - info@rethink.org - www.rethink.org
Schizofreniförbundet		Sweden	Hantverkargatan 3G, S-11221 Stockholm - Tel. +46 8 545 55 980 office@schizofreniforbundet.se - www.schizofreniforbundet.org.se
SHINE		Ireland	Supporting People Affected by Mental Ill Health 38 Blessington St, IRE-Dublin 1 - Tel. +353 1 860 16 20 info@shineonline.ie - www.shineonline.ie

Full members - continuation from previous page

Similes Fr		Belgium	Fédération des Associations SIMILES Francophones a.s.b.l. Rue Malibran 39, B-1050 Bruxelles, Tel. +32 2 64 444 04 federation@similes.org - www.similes.org
Similes VI		Belgium	Federatie van Vlaamse SIMILES kringen v.z.w. Groeneweg 151, B-3001 Heverlee - Tel. +32 16 244 201 info@similes.be - www.similes.org
SIND		Denmark	Landsforeningen Jernbane Allé 45, 3 sal, DK-2720 Vanløse - Tel. +45 35 24 07 50 Landsforeningen@sind.dk - www.sind.dk
SOFPSI N SERRON		Greece	Association of Families and Friends for Mental Health Country of Serres 13A Tsalopoulou Str. GR-62123 Serres, Greece Tel. +30 23210 63388 - Fax +30 23210 63559 sofpsi-s@otenet.gr - www.sofpsi-ser.gr
SOPSI Athens		Greece	Πανελληνιος Σύλλογος Οικογενειών Για Την Ψυχική Υγεία Delou Str. 3, 16231 GR-Vironas - Tel. +30 107 64 02 77 sopsi@ath.forthnet.gr - www.iatronet.gr/sopsi/
SOPSI Patras		Greece	6, Sissine Str, GR-26225 Patra, GREECE Tel +30 2610 621 273 sopsipatron@yahoo.gr - www.sopsipatron.gr
Stichting Labyrint ~in Perspectief		Netherlands	Postbus 12132, NL-3501 AC Utrecht- Tel. +31 30 254 68 03 secretariaat@labyrint-in-perspectief.nl - www.labyrint-in-perspectief.nl
Support in Mind Scotland		UK Scotland	Unit 6, Newington Business Centre, Dalkeith Road Mews, GB-Edinburgh H16 5DU - Tel. +44 131 662 4359 info@supportinmindscotland.org.uk - www.supportinmindscotland.org.uk
SYMPATHEA o.p.s.		Czech Rep.	Celovárodní Organizace Duševně Nemocných Bulharská 26, 101 00 Praha 10 - Tel. +420 777 240 504 (Mob) sympathea@sympathea.cz - www.sympathea.cz
UNAFAM		France	Union Nationale des Amis et Familles de Malades Mentaux 12 Villa Compoint, F-75017 Paris - Tel. +33 153 06 30 43 infos@unafam.org - www.unafam.org
UNASAM		Italy	Unione Nazionale delle Associazioni per la Salute Mentale c/o Istituzione Minguzzi, Via Sant Irain 90, I-40123 Bologna Tel. +39 051 5288526 - ernestomuggia@tin.it - www.unasam.it
VASK Schweiz		Switzerland	Vereinigung der Angehörigen von Schizophrenie-/ Psychisch Kranken Langstrasse 149, CH - 8004 Zürich - Tel. +41 44 240 1200 info@vask.ch - www.vask.ch
Vereniging Ypsilon		Netherlands	Postbus 715, 3000 AS Rotterdam, Tel. +31 88 000 21 20 ypsburo@ypsilon.org - www.ypsilon.org

EUFAMI affiliate members

APHCA		Greece	Association for the Psychosocial health of Children & Adolescents 19, Aghiou Ioannou Theologou str., GR - 15561 Cholargos (Athens) Tel. +302106546524 info@epsype.gr - www.epsype.gr
ENCONTRAR+SE		Portugal	Association to support people with severe mental illness R. Henrique Lopes de Mendonça, n° 253 Ap. 22., P - 4150 - 396 Porto Tel. +351919060165 encontrarse.pt@gmail.com - www.encontrarse.pt
METIS Europe asbl		Belgium	Rue Kelle 94, B - 1150 Brussels Tel. +32 2 384 47 74 - www.metis-europe.eu
MTKL		Finland	Mielenterveyden Keskuslitto ry Ratakatu 9, 00120 Helsinki - Tel. +358 9 5657 730 timo.peltovuori@mtkl.fi - www.mtkl.fi
Progetto Itaca Onlus		Italy	Via Alessandro Volta 7/A - I-20121 Milano Tel. +39 026 269 5235 segreteria@progettoitaca.org - www.progettoitaca.org
ŠENT		Slovenia	Slovensko združenje za duševno zdravje Cigaletova ul.5, SL-1000 Ljubljana - Tel. +386 40 221 989 mimeo@amis.net - www.sent.si