Introduction

It is a great pleasure for me to introduce EUFAMI’s Annual Report for 2014. This was another year of valuable work on behalf of our member associations and all those whom they, in their turn, support. Our goal remains the same as ever – to promote better understanding and better services for people with mental illness through our clear focus on family members who play such an indispensible role in the provision of care.

The report includes news from our members individually and records our own activities in representing them in a wide variety of international forums. These include conferences and other events organised by the major clinical associations, relevant voluntary bodies, European Union institutions, research project boards and the World Health Organization.

Our continuing engagement with such professional interests is paying significant dividends at a modest cost. It demonstrates that EUFAMI is accepted as a valued and regular member of the broad community of mental health specialists and organisations; it strengthens our formal and informal relationships with like-minded experts in related fields; and above all it ensures that the voice of family carers of people with mental illness remains prominent and is not overlooked. In a word it sustains our influence on behalf of our members and those whom they serve.

Of the many developments in 2014, I would highlight two for particular mention. First is the EUFAMI Caring for Carers (C4C) Survey of the experiences of carers for persons with schizophrenia. This was conducted with LUCAS, the research arm of the University of Leuven, and its initial results were published and widely disseminated for World Mental Health Day. They confirm in statistical terms the scale of carers’ contribution and the huge, sometimes overwhelming, emotional burden placed on them. Nearly half reported a degree of dissatisfaction with the support they receive from medical and healthcare staff and nine out of ten said they want more support. The Survey is potentially of significant benefit to many organisations and policy makers. We shall continue to encourage its use in informing discussions about priorities and actions in support of family carers.

Secondly I must mention the Members’ Planning Day for delegates from the associations which we held in November. Its starting point was a paper approved by the Board outlining a medium term strategy with three specific objectives: to extend our presence in central and eastern Europe; to strengthen our arrangements for supporting our members and involving them in our affairs; and to deepen our influence with professional bodies, policy makers and others who matter to us. The Day produced a rich collection of ideas and suggestions around these objectives which will guide our sense of direction over the next few years ahead.

May I conclude as last year by thanking again all those who connect with us in whatever way. The need for EUFAMI and its member associations in bringing some relief in the everyday life of mentally ill people and their families remains as great as ever. And as this report shows, much inspirational work is in fact being done.

Bert Johnson
EUFAMI President
**BapK – Germany**
During the 6th Week of Mental Health in Berlin, Germany, BapK offered workshops and an ‘Open Day’ at the Berlin office of the Berlin Carers Association. BapK’s information project ‘SeeleFon’ (Phone for the Soul) continued with the support of municipalities and a project which developed carer-oriented support methods for the children of mentally ill parents. The BapK Homepage was officially certified. In cooperation with the Muttergesundungswerk (Health Charity for Mothers), a three-week health holiday for mothers and partners of children with mental illness and husbands was offered in Baden-Württemberg. Other activities included - Workshop for employed and voluntary staff of carers associations in Germany, training in counselling strategies, exchange of experiences. Amongst ongoing activities is a government sponsored project on how to deal with domestic violence and de-escalation strategies for families with mentally ill family members. BapK, Germany was given permission by EUFAMI to develop five new modules for the Prospect training Programme (for family and friends). The themes of the new modules are:

- Continuing Prospect journey
- Feelings as guilt experienced by family members/friends
- Feelings of shame experienced by family members/friends
- Life management of family members/friends – what is it? How do I react to the changes that life brings?
- Me now

FinFami was evaluated the effectiveness of Prospect groups for family and friends. The study provides evidence that the groups positively affect the family members’ wellbeing. FinFami also implemented a project which developed carer-oriented support methods for municipalities and a project which developed support methods for the children of mentally ill parents.

**FEAFES - Race in Madrid**
FEAFES, the national organisation in Spain which encompasses all the federations and associations of people with mental illness and families, totalling 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.

In 2014, a good example of how FEAFES helps to raise awareness of mental illness was their celebration of the World Mental Health Day in October; this included an awareness workshop that was hosted in the Health, Social Services and Equality National Department, in Madrid on the 6th October around the claim ‘Opening minds, closing stigma’. It was focused on making society aware of the situation of people with mental health disorders and their families, as a way to eradicate the prejudices against them and that constitute one of the most important obstacles in their day-to-day life.

FEAFES also celebrated a popular race in Madrid on the 18th October with the objective of promoting and effectively showing the integration of people with mental disorders and more than 600 people all around Spain participated in it. Finally, the Social Theatre Group “La Rueda” presented a stage play based on different mental disorders. FEAFES developed several advocacy and lobbying actions during 2014, by taking part in the analysis on the Reform of the Spanish Penal Code and its impact on the rights of people with mental illness and the presentation of their “PARTISAM Guide”, which is intended to promote the development of actions, activities, attitudes and commitments to increase the effective participation of users of mental health services.

FEAFES developed a special programme for its regional federations named ‘Promotion of Mental Health and Prevention of Exclusion’; this has allowed FEAFES to work with regions on subjects like good practices on external communication and mental health information services and training courses for spokespersons. A guide and training materials about dual diagnosis was developed.

**FEAFES - Spain**
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**FinFami – Finland**
The purpose of the FinFami is to support 17 member associations and look after the interests of the family members at the national level. FinFami, founded in 1981, develops family work in cooperation with other organisations in the mental health sector and takes part in social conversation. Its values are respect, trust, warmth, humanity, transparency and co-operational competence.

FinFami was given permission by EUFAMI to develop five new modules for the Prospect training Programme (for family and friends). The themes of the new modules are:

- Continuing Prospect journey
- Feelings as guilt experienced by family members/friends
- Feelings of shame experienced by family members/friends
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FinFami evaluated the effectiveness of Prospect groups for family and friends. The study provides evidence that the groups positively affect the family members’ wellbeing. FinFami also implemented a project which developed carer-oriented support methods for municipalities and a project which developed support methods for the children of mentally ill parents.

**Hafal – Wales**
2014 was a historic year for Hafal - the Welsh mental health charity. Hafal purchased a new building for its Recovery Centre which will provide the first in-patient service. The organisation is well on the way to developing its most advanced service to...
date, delivering a unique Recovery Programme to clients with high needs who, despite the best efforts of the mental health service for 50 years, were in need of hospital treatment which is ambitious for its clients and which sets new standards of best practice for Wales. It will be user-led and recovery will be its objective.

Apart from this huge development, 2014 has been an action-packed year for Hafal. An example is its ‘Our Let’s Get Physical’ campaign which aims to address the inequalities in physical health faced by people with a mental illness and their carers. Over 15,000 people took part in the campaign’s physical exercise and healthy eating activities and the physical health checks in Hafal’s mobile health clinic.

Hafal was awarded £150,000 by Comic Relief and nearly half a million pounds by the Big Lottery to run two separate projects which aim to support people with a mental illness in the Criminal Justice System. The new initiatives will help to ensure that offenders with a mental illness get access to the support they need - and break the cycle of reoffending. They were also awarded £80,000 by the Welsh Government to deliver their groundbreaking ‘Reaching Out’ project in 2015–18. The funding will support the charity’s work to reach out to a high proportion of all people using secondary services, and those with a serious mental illness supported by primary care, as well as their carers.

The project will equip those people with the tools they need to work in partnership with services and take key steps towards recovery.

Humana - Slovenia

Humana is the Slovenian organisation which is primarily devoted to help family members of people with mental health issues. The organisation has been in existence for 15 years and has expanded in both influence and diversity of services. In 2014 Humana was active in different areas, organising 278 public events, 14 educational events all around Slovenia and 33 in its home town of Kranj. Humana also held a lecture during a Brain Health Awareness Week; which was organised by SINAPSA – the Ministry of health of Republic of Slovenia, City municipality of Kranj and Municipality of Našo and Employment Service of Slovenia.

The meeting received good media coverage.

Kinapsi - Greece

Kinapsi (Movement of Siblings of People with Mental Health Problems) organised a public awareness event on ‘Empowerment of Families of People with Mental Illness’ in Athens. About 200 delegates attended, representing family associations from Greece and Europe, people with psychiatric experience and mental health professionals. The conference was held at Auditorium 864 in Athens under the auspices of the Greek Presidency of the European Union, the City of Athens and the Greek Ministry of Health. The meeting received good media coverage.

The themes included in the event were:

- The rights of persons with mental illness and their families in Greece; discussion of legal issues concerning recipients of mental health services.
- Structures for low-cost mental health support; the contribution of technology (help lines, tele-psychiatry, internet consultation, virtual reality, games, e-health, mobile health, etc.).
- The implications for the mental health of siblings of people with mental illness.

Catering services were provided by a mental health social enterprise company, Ev Zoen (Living Well). Kinapsi is a self-help organisation for people who have a brother or sister with a mental illness. It offers social programmes to provide networking opportunities and support for caregivers.

Rethink Mental Illness - England

2014 was a hugely significant year for Rethink Mental Illness, a year leading up to a General Election in May 2015 to elect a new UK Government. During 2014 there was an unprecedented political focus around what can be done to improve outcomes for people with mental health problems and to genuinely achieve what is often called ‘parity of esteem’ with physical health. In October, following a period of intensive influencing activities with colleagues in the mental health sector, the organisation secured the first ever waiting time target for access to mental health services (for treatment living well-care) which was an important victory that will herald in a maximum waiting time of 14 days for early intervention services for people experiencing a first episode. Following the introduction of the Health and Social Care Act three years ago a series of new organisations were created to oversee and deliver health reforms in England. One of those, the independent health sector regulator, Monitor, is responsible for setting the ‘tariff’ or price value for mental health services and budgets, which have been proposed reducing spend on NHS services across the board – a flat rate of 1.9% reduction. This decision was based on data from general hospitals and applied equally to mental health services.

Along with our 23,000 activists we worked hard to raise the profile of this issue, given that mental health services are chronically underfunded.

The level of public profile for Rethink Mental Illness also grew in 2014. More and more journalists are making contact for comment about the issues and the existential threat posed by such underfunding and as a result of this media attention Rethink Mental Illness’s ranking in the Charity Brand Index has improved significantly. Its ‘Finding Mike’ campaign attracted huge international attention in 2014 and will be broadcast on one of the UK’s main terrestrial TV channels, Channel 4, in April 2015. The organisation’s website continued to be one of the main routes through which information and advice to over 200,000 visitors each month is provided, with over 1.9 million fact-sheets downloaded in 2014. Social Media was also a very important platform for Rethink Mental Illness and with over 175,000 Facebook and Twitter followers a highly successful 1-hour Facebook Q&A with Deputy Prime Minister Nick Clegg was hosted, which reached 140,000 people over 48 hours. The Time to Change campaign was granted funding for 2015/16 and Rethink Mental Illness will continue to build on its fantastic track record of challenging stigma and discrimination. This year the 3,000th organisation pledged to improve mental health. As the role of the organisation to support carers of people with mental illness, the organisation’s 66 registered carers groups met in locations all around the country. A further 30 combined carer and service user groups and two sibling groups also met on a regular basis.

The organisation continues to provide the provision of information and mutual support as a core activity. Other Groups focus on leisure activities or on campaigning or fundraising.

Finally, in a year of significant change a new Chief Executive was appointed. Mark Winstanley, who has been with Rethink Mental Illness for several years, recently stepped up to steer the organisation through these turbulent but exciting times.

Hafal Members on an away day

Humana member and President of Slovenia, Mr Borut Pahor

Kinapsi - public awareness event in Athens
Shine - Ireland
During 2014 Shine continued to provide a full range of services to just over 18,000 people. This was achieved despite a series of reductions in statutory funding over the previous six years. As in previous years, Shine provided direct day resource provision through the Basin and Basement resource services in Dublin and Cork respectively. These services operate excellent models of individualised service provision and provide valuable support to people with severe mental health problems.

During 2014 Shine continued to publicise its campaign on Family Friendly Mental Healthcare Services. This campaign aims to ensure that the voice of the family member is heard by mental health service providers. During the course of the year the organisation met with a range of professional organisations and mental health care service providers and it continues to support family members who advocate on this important issue. In collaboration with the HSE Southeast, Shine continued the development of a new recovery project based in Waterford. This service is planned to commence in the first half of 2015. This service of excellence in Waterford City will become a recovery hub for individuals and their families in the region.

Shine, in association with EUFAMI cooperated in a major European wide survey of family member’s opinions and concerns. See Change (www.seechange.ie), the stigma reduction partnership continued to grow and during 2014 See Change launched its second Green Ribbon campaign, during which 350,000 ribbons were distributed. See Change has also expanded its Mental Health in the Workplace programme and has now engaged with 26 companies to bring good mental health policies and practices into the workplace.

Headline (www.headline.ie), the national media monitoring service has continued to be a very useful source for family members who often are forced to take protective measures for their loved ones. During 2014 Shine continued its work on adhering to a recognised code of practice for good governance of community, voluntary and charitable organisations in Ireland. The Council of Shine also agreed to the establishment of a governance sub group of council and an annual external governance audit. Shine has now achieved compliance with the Code of Governance for the community, voluntary and charitable sector in Ireland.

Similes Flanders – Belgium
Belgium is one of the few European countries, where euthanasia in case of severe and unbearable psychological distress is authorised by Law (2002). Since almost every person, who carried out euthanasia, is member of a community and has a family, the question arises, what happens with the surviving relatives after an active euthanasia. Similes does not take a position in this ‘ending of life’ debate and there is no pro or contra point of view. Similes only wishes to draw attention on the impact for the surviving relatives of a person with mental illness who carried out euthanasia and pleads for more support and assistance for them, whether they are children, parents or simply relatives. In most of the cases, the doctor who administers the lethal injection does not take into consideration the fate of the family members. They feel left alone after the decease of their loved one, even more when it sometimes occurs that the person with mental illness did not inform his relatives about his euthanasia decision.

During 2014, Similes Flanders organised four training sessions for families of people with mental illness, on the New Belgian Law on protection of vulnerable persons. Among the matters discussed were:
- Is the appointment of an administrator for the mentally ill or vulnerable person, not ‘a bridge too far’?
- Who can turn in an application to appoint an administrator?
- How is taken care of the incapacity at personal level?
- What if you cannot obtain a medical certificate to ask for the protection of a mentally ill person?

Often there is a thin line and Similes recommends a distinction between protective measures for a vulnerable person itself and measures to protect the material goods of that person. There are still a lot of grey zones in this new Law. Similes tries to clear as much as possible the difficulties for family members who often are forced to take protective measures for their loved ones.

On Saturday 18th October 2014, Similes organised a Conference under the theme ‘What after us’.

This very successful conference was intended as an informative day for parents of a mentally ill/vulnerable child. A range of specialised speakers such as lawyers, financial experts, professional health carers as well as parents tried to bring hopeful solutions for the specific situation which occurs when mentally ill/vulnerable children inherit from their deceased parents. Many relevant topics were covered during the day. The large audience and the multitude of questions was once again proof of how many parents worry over these important matters.

SIND - Denmark
During 2014 SIND continued to provide its comprehensive range of services to facilitate users and their relatives. Among these services are the 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 others who need to learn from our experience.

In 2014 SIND further strengthened its work to influence political decision makers at local, regional, national and international level. In 2014 SIND joined the NGO delegation who attended the meetings in UN’s Committee on the Rights of Persons with Disabilities where Denmark’s compliance with the Convention on the Rights of Persons with Disabilities was evaluated. SIND also continued to be very visible in the media. An independent survey showed that mental health was the health issue covered most in Danish media in the first 4 months of 2014. After the Minister for Health, SIND’s President was the most cited person in media when it came to mental health issues.

Ypsilon - The Netherlands
How to build a family friendly policy – a new Dutch approach
Imagine 1 in 4 will experience psychotic or psychiatric problems during their life time. And imagine each of them has 2 close relatives. That’s not overdone, is it? That means 1 in 2 is a family member. That’s half of Holland (and the rest of the world) not only in general way, but also of the people working in psychiatric services. At least! But why don’t you see them that much? And in case they would, wouldn’t there be a much better policy to have a family friendly approach? Because they know what it is to be a relative? That is the bottom line of an interesting new project the Dutch association Ypsilon started in 2014.

In the project several steps are taken to see whether this hypothesis is right or not. Via a questionnaire Ypsilon asked relatives whether they thought they are better treated in case it is done by a professional who is also a relative to someone suffering from a psychiatric disease. ‘Yes, that’s correct’ answered 79% of its members (N=505). And do you think you are a better professional? ‘Yes, I am’, answered 77% of the 215 professionals with family experience. And are they willing to promote more openness about being a relative? ‘Yes’ answered 56%, ‘maybe’ answered another 34%.

With these stimulating figures, Ypsilon approached various psychiatric institutes and asked if they would be a testing ground. Currently, they are working with three institutes. The main reason why professionals are not open about their family experience is because they do not feel safe to do so. That is why Ypsilon asked a statement from their board in which their employees are stimulated to be open.

In the next step two of the identified professionals with family experience per testing ground are being trained. Partly to become their own trainer of a well known training in interaction skills (www.demat.eu). And in addition they follow two different workshops. One about fighting stigma and being open to their colleagues and in the other they learn how to look with the eyes of a family member to the family policy of their own institute. Peer2Peer is the name of this project, because these people are peer to their colleagues, but also peer to the family members. 2015 will be the year of the truth.

NEWS FROM THE MEMBERS OF EUFAMI
EUFAMI Strategy 2012 – 2015

EUFAMI, currently registered and based in Belgium, is a Federation of national and regional family organisations from across Europe.

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
- 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.

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.

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 what is expected of them. 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.
During the Board of Directors met on four occasions - three times at the EUFAMI office in Leuven and a fourth in Athens. The General Meeting of EUFAMI took place in Athens in June and a Member Training day was also arranged to take place in conjunction with the General Meeting. In June, a Member Cluster meeting also took place in Athens and a Planning Day for Member Associations was held in Leuven in November.

EUFAMI Board of Directors Meeting - 7th March 2014 - Leuven, Belgium
After the President opened the meeting and the minutes of the previous Board meeting were approved, the Secretary General provided an update on the current ongoing work at EUFAMI. He reported having received positive feedback on the EU election toolkit which had been recently made available to the EUFAMI member associations and that the first EUFAMI Congress is due to take place in 2015.

EUFAMI Board of Directors Meeting - Athens, Greece - 5th June 2014
The first item on the agenda of the meeting was the approval of the minutes of the previous Board meeting. A member planning day took place in Leuven attended by 18 member representatives. The following objectives were set for the day - to deepen members’ connections with each other, to reflect on EUFAMI’s 2012-15 strategy and to plan for the possible venues for the next General Meeting.

EUFAMI Annual General Meeting - Athens, Greece - 7th June 2014
The President opened the meeting, after registration of delegates was completed, by welcoming all of the delegates.

EUFAMI Internal Meetings 2014
EUFAMI Internal Meetings 2014

EUFAMI Board of Directors Meeting - Leuven, Belgium - 13th September 2014
After the President welcomed everyone to the meeting the minutes of the previous Board meeting were approved, the draft minutes of the General Meeting and agreed to be an accurate record of the proceedings. A review of the Member Training Day, held in Athens in June, took place. The Board members then discussed a number of membership and governance issues; the following topics were covered:

1. Review of the amended statutes which had been approved in 2012.
2. The draft minutes of the General Meeting held in Dublin in May 2013 were reviewed and approved by the delegates as an accurate record of that meeting.
3. An update on the current financial position and the Board progressed the draft Position Paper on Early Intervention in Psychosis with a view to having it tabled at the next General Meeting for approval.

EUFAMI Member Planning Day - Leuven, Belgium - 28th November 2014
A member planning day took place in Leuven attended by 18 member representatives. The following objectives were set for the day - to deepen members’ connections with each other, to reflect on EUFAMI’s 2012-15 strategy and to plan for the possible venues for the next General Meeting.
Reflections, through the camera eye, of some of the work and activities of EUFAMI members through 2014
EUFAMI Representation

(some examples from 2014 where EUFAMI was represented at various conferences and external events by members of the Board, other EUFAMI members and staff and EUFAMI member associations; it is not a complete record due to space limitations)

January
The Secretary General represented EUFAMI at a Workshop on Mental Health Research which was organised by Directorate General for Research in Brussels on the 22nd January.

On the 30th and 31st January, the Secretary General attended the conference entitled ‘How to promote empowerment experiences for Mental Health users and carers in Europe?’ in Lille, France. The conference was organised by WHO Europe and the WHO Collaborating Centre in Lille. He spoke at the session on ‘Opinions of European representatives of service users, carers, and families about indicators of good practices’.

February
A meeting of the European Parliament Special Interest Group on Mental Health and Well Being was held in the Parliament in Brussels on the 11th February. The meeting focused on the subject of alcohol and mental health and EUFAMI was represented by Nadine Fossion, EUFAMI Board member from Belgium.

The President, Bert Johnson, Martine Frager-Berlet, Board member, and the Secretary General travelled to Luxembourg on the 14th February to attend a meeting with representatives from DG Sanco. Mr John F Ryan, Acting Director, DG Health and Consumers, along with Jürgen Scheftlein and Wolfgang Philipp represented DG Sanco.

March
From the 1st to the 4th March, the European Psychiatric Association (EPA) 22nd European Congress of Psychiatry took place in Munich, Germany. EUFAMI was represented at the event by the President, Bert Johnson, and Sigrid Steffan, past President.

A meeting of the International Working Group on Social Inclusion and Schizophrenia, facilitated by Roche took place in Vienna, Austria on the 3rd March. EUFAMI is represented on this working group by its Secretary General.

On the following two days, 4th and 5th March, the Secretary General attended an International Patient Meeting also held in Vienna.

The Patient Think Tank meeting organised by EFPIA took place in Brussels on the 10th March.

The Secretary General represented EUFAMI at the Expert Platform on Depression meeting held in Brussels on the 12th March.

Mr John Saunders, EUFAMI Board member, attended a meeting of the members of Work Package 5 of the EU funded project ‘Joint Action on Mental Health and Well Being (JAMHWW). The meeting took place in Bologna, Italy on the 17th and 18th March.

EUFAMI was represented by Martine Frager-Berlet, Board member, at the EU Conference ‘Health in Europe – making it fairer’, organised in Brussels by DG Sanco. The meeting took place on the 18th March.

April
Bert Johnson, EUFAMI President, and Nadine Fossion, Board member, attended and actively participated at the 2014 EU Summit on Chronic Diseases held in Brussels on the 3rd and 4th April.

John Saunders, Board member, spoke at the 4th International Conference ‘A coin with many sides: Perspectives on mental illness from different professionals’ held in Wroclaw, Poland from the 3rd to the 5th April. The conference was organised by the Young Psychiatrists Network – psynet.

Alessandro Svettini, another EUFAMI Board member, attended and spoke at the 7th Geneva Conference on Person Centred Medicine organised by the International College On Person Centred Medicine (ICPCM). The conference took place in Geneva, Switzerland on the 29th and 30th April.

May
The Annual General Meeting of the European Patients Forum took place in Brussels on the 12th and 13th May and Bert Johnson, President, represented EUFAMI.

The 17th World Congress of Psychiatry – Focusing on Access, Quality and Human Care took place in Madrid from the 16th to the 18th September in Madrid, Spain. EUFAMI’s Spanish member association, PEFES, attended the Congress.

The Secretary General also attended the 26th ECNP Congress which was held in Barcelona from the 5th to the 8th October and participated at the ECNP Collaborative Forum which took place during the Congress.

On the 7th October, Nadine Fossion, Board member, spoke at a meeting in the European Parliament organised by Garnian Europe, European Brain Council, EUFAMI, EuroCarers and the WFMH - Living with Schizophrenia. The critical role of carers was further emphasised when the initial results from the EUFAMI major Family Carer survey were presented at the same meeting. The EUFAMI Secretary General also took part in the meeting.

June
A meeting of the European Unified Suicide Prevention Platform (EUSPP) took place in Brussels on the 19th June and the Secretary General attended and represented EUFAMI.

The Secretary General and Rita Geerts, EUFAMI office administrator attended a workshop on Media and Communications Strategy organised by a number of advocacy groups, including EUFAMI. The workshop took place in Brussels on the 20th and 27th June and was supported by Janssen.

July
A further meeting of the Patient Think Tank took place in Brussels on the 1st July.

A Roundtable meeting on Alcohol took place in Brussels on the 4th July, organised by Lundbeck. The Secretary General attended and contributed to the meeting.

September
On the 4th and 5th September, John Saunders, Board member, represented EUFAMI at the mhGAP Forum organised by the WHO in Geneva, Switzerland.

A meeting of the International Advisory Board on Schizophrenia took place in Washington on the 4th 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. He also attended a number of sessions at the annual convention of NAMI which was also being held in Washington at the same time.

The 16th World Congress of Psychiatry – Focusing on Access, Quality and Human Care took place in Madrid from the 16th to the 18th September in Madrid, Spain. EUFAMI’s Spanish member association, PEFES, attended the Congress.

October
On the 1st October, the Secretary General attended an event in the European Parliament to mark Depression Day.

The Secretary General also attended the 26th ECNP Congress which was held in Barcelona from the 5th to the 8th October and participated at the ECNP Collaborative Forum which took place during the Congress.

On the 7th October, Nadine Fossion, Board member, spoke at a meeting in the European Parliament organised by Garnian Europe, European Brain Council, EUFAMI, EuroCarers and the WFMH - Living with Schizophrenia. The critical role of carers was further emphasised when the initial results from the EUFAMI major Family Carer survey were presented at the same meeting. The EUFAMI Secretary General also took part in the meeting.

At an International Congress, held in Athens from the 9th to the 11th October, Connie Magro, Vice President, also presented the initial results of the Family Survey and spoke about the role of the family caregiver at the Congress.

Rita Geerts, EUFAMI administrator, delivered a presentation on behalf of the Secretary General (who could not attend in person) at the European Carers intergroup meeting in the European Parliament on the 15th October. The meeting was dealing with the the Social Protection Committee report on long term care.

A high level conference on ADOCARE, the EU funded project dealing with young people and adolescents was held in the European Parliament on the 16th October. Nadine Fossion, Board member, was included on the attendees list of the conference.

EUFAMI had an exhibition stand at the 21st ECNP Congress which took place in Berlin from the 18th to the 21st October. The EUFAMI President, Bert Johnson, and the Secretary General were in attendance at the Congress.

The President, Bert Johnson, attended a one day conference in Athens.
EUFAMI Family Survey

The majority of (family) carers live with the illness 24 hours of the day, each day of the year. Meeting the expressed needs of family caregivers will quicken the recovery of their loved ones.

Caring for Carers (C4C) SURVEY - Experiences of Family Carers of persons with mental illness

Introduction and aim of the C4C Survey

The C4C Survey is an international survey being undertaken by EUFAMI in collaboration with LUCAS, the centre for care research and consultancy at the University of Leuven, to understand the needs and challenges faced by carers supporting those living with a mental health illness. The survey, the first of its kind, is being conducted in 26 countries in total (Austria, Belgium, Cyprus, Czech Republic, Denmark, Finland, France, Germany, Greece, Ireland, Israel, Italy, Lithuania, Malta, Netherlands, Norway, Portugal, Russia, Slovenia, Spain, Sweden, Switzerland, the UK as well as Australia and Canada) and final results are expected in mid 2015.

Initial results, released on 10th October 2014, highlight findings from France, Germany, Italy, Spain, the UK as well as Canada and Australia. The survey (covering more than 400 people caring for relatives with severe mental illness, in particular schizophrenia) was conducted to understand the needs and challenges of carers.

There is already a general recognition that carers’ needs are closely linked with those of the person they care for; however this survey was designed specifically to find out about the circumstances and burdens linked with those of the person they care for, however this survey was designed specifically to find out about the circumstances and burdens faced by carers supporting those living with a mental health illness. The survey, the first of its kind, is being conducted in 26 countries in total (Austria, Belgium, Cyprus, Czech Republic, Denmark, Finland, France, Germany, Greece, Ireland, Israel, Italy, Lithuania, Malta, Netherlands, Norway, Portugal, Russia, Slovenia, Spain, Sweden, Switzerland, the UK as well as Australia and Canada) and final results are expected in mid 2015.

Initial results, released on 10th October 2014, highlight findings from France, Germany, Italy, Spain, the UK as well as Canada and Australia. The survey (covering more than 400 people caring for relatives with severe mental illness, in particular schizophrenia) was conducted to understand the needs and challenges of carers.

Why the carer?

Community-based care and prevention is now preferred over long-term hospitalisation for people with mental health conditions, and the responsibility for care has shifted from hospitals to informal carers, such as a relative. Carers fulfil a distinct and important role by providing support and advocating for their ill relatives as well as contributing to their recovery. The relapse rate at 2 years was 40% in patients whose families received psychotherapeutic support, compared with 75% in those whose families received no help. Caring for someone with schizophrenia takes time, energy, financial and emotional resources.

In 2012, the estimated total cost of psychotic disorders such as schizophrenia in Europe (the 27 members of the EU, plus Iceland, Norway, and Switzerland) amounted to €29.0 billion - equivalent to €5805 per patient per year. Despite the essential role that family carers perform, they are not fully recognized as crucial partners in care so far. Although caregiving may give rise to positive feelings and experiences, carers feel highly exposed and caring for a relative with mental illness is related to high personal suffering, feelings of guilt, helplessness, fear, vulnerability, anxiety and anger. When a mental illness ‘enters’ the family circle, family members tend to remove themselves from their natural support networks for a number of different reasons. Additionally, at the age of onset of a child’s mental illness, the age of family carers (40–60 years) and the possibility of separation or divorce mean that they are at a time of great family stress and pressure (figure 1). Given that the frequency and intensity of psychotic episodes is unpredictable in those with schizophrenia, coping with such a condition poses ongoing challenges to family carers.

The purpose of the survey is to capture and document the experiences and well-being of family caregivers of persons living with mental illness, giving us more insight into the caregiver’s role in mental disease management. Some of the key findings from the first phase are shown on the following page.
**Detail of Income**

<table>
<thead>
<tr>
<th>1. Core 2014 2013</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Janssen</td>
<td>EUFAMI Collaborating Partner Programme</td>
</tr>
<tr>
<td>Lilly</td>
<td>EUFAMI Collaborating Partner Programme</td>
</tr>
<tr>
<td>Lundbeck</td>
<td>EUFAMI Collaborating Partner Programme</td>
</tr>
<tr>
<td>Hoffmann - La Roche AG</td>
<td>EUFAMI Collaborating Partner Programme</td>
</tr>
<tr>
<td>Takeda</td>
<td>EUFAMI Collaborating Partner Programme</td>
</tr>
<tr>
<td>Total</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>2. Projects 2014 2013</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Hoffmann - La Roche AG Family Survey</td>
<td>€ 6,950</td>
</tr>
<tr>
<td>Lundbeck</td>
<td>Family Survey</td>
</tr>
<tr>
<td>Hoffmann - La Roche AG Healis</td>
<td>€ 0</td>
</tr>
<tr>
<td>Delegate Fees</td>
<td>Dublin Conference</td>
</tr>
<tr>
<td>Hoffmann - La Roche AG Oxford University Schizophrenia Project</td>
<td>€ 176,546</td>
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<tr>
<td>Total</td>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>3. Other Support 2014 2013</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Takeda Honoraria for Training Day</td>
<td>€ 0</td>
</tr>
<tr>
<td>Takeda Giving tree initiative at ECNP congress</td>
<td>€ 6,000</td>
</tr>
<tr>
<td>Total</td>
<td></td>
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</table>

**Audited Financial Results for 2014 - Commentary**

Income

The amount of funding which EUFAMI received for support of its core operations under the EUFAMI Collaborating Partner Programme dropped significantly in 2014; from €130,000 in 2013 to €85,000 in 2014. The reason for this lower amount is quite simple - companies reduced the amounts they contributed to the programme and in one case, ceased altogether to renew membership. Of course this reduced income put a lot of pressure on EUFAMI’s core operations and brought back the total funds received from our partner programme to the level received in 2012. EUFAMI wishes to acknowledge the support which it received in 2014 from its partners. With respect to project related income, I am once again happy to report an significant improvement - an increase of €115,692 from €124,829 in 2013 to €240,521 in 2014. The project funding in 2014 related to two main projects - the first being the funding received from Hoffmann-La Roche for year 2 of the schizophrenia related project with Oxford University Hospital and the second tranche of project funding was received from Lundbeck for the EUFAMI major survey on Family Carers. All other income in 2014, although lower than in 2013, was in line with expectations. Membership fees for 2014 were almost halved when compared with fees for 2013. This was as a result of a Board proposal and a General Meeting decision to reduce fees to a more realistic and affordable level in response to the overall downturn in the economies in Europe and worldwide. It should also result in a reduction over the coming years of the amount we will have to write off for bad debts.

Expenditure

There was a very slight increase in staff related costs in 2014 over 2013; this small increase was due to normal wage increases. As I mentioned last year, we are only reporting on one line for Board costs - if you recall, we reported over two lines in 2013 due to the change mid-year caused by the transition of the Executive Committee into the new Board structure. Overall, there was a reduction in Board costs in 2014. There is a significant increase in the amount which we are reporting for Bad Debts write off. A decision was taken to clear a healthy state at the end of December 2014 amounts to anybody that we are reporting a loss for 2014. However, with continuing prudent control of costs and with lots of goodwill and co-operation by staff and Board, we have managed to keep this loss to €10,327. Although a loss is never good news, our finishing position should be considerable as acceptable when one takes into account the amount of bad debts we have provided for in this year’s accounts.

However, the situation going forward is very challenging. Especially when one considers that EUFAMI is scheduled to organise its 6th European Congress in 2015. Realistically I cannot envisage any great improvement in our funding efforts for 2015. Therefore I would like to send out an early warning that it is most probable that for 2015 and possible 2016, we may need to draw on our reserves to get us safely through these coming years, in terms of finance. Additionally, during 2015 there will be a transition period in the post of Secretary General at EUFAMI. This process in my opinion will add uncertainty to our funding scenario for 2016 and may exacerbate our reliance on reserves in the short term.

Also the EUFAMI balance sheet overall is in a healthy state at the end of 2014. Cash at Bank at the end of December 2014 amounts to €326,622 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

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**Balance Sheet**

<table>
<thead>
<tr>
<th>Assets 2014</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fixed assets</td>
<td>€ 0</td>
</tr>
<tr>
<td>Furniture</td>
<td>€ 0</td>
</tr>
<tr>
<td>Other tangible assets</td>
<td></td>
</tr>
<tr>
<td>Current assets</td>
<td>€ 346,292</td>
</tr>
<tr>
<td>Trade debtors</td>
<td>€ 21,975</td>
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<tr>
<td>Other amounts receivable</td>
<td></td>
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<tr>
<td>Current investments</td>
<td></td>
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<tr>
<td>Cash at bank and in hand</td>
<td>€ 322,627</td>
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<tr>
<td>Transitory accounts</td>
<td>€ 1,695</td>
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<tr>
<td>Total assets</td>
<td>€ 346,292</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Liabilities 2014</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Capital and reserves</td>
<td>€155,387</td>
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<tr>
<td>Allocated funds</td>
<td>€ 44,293</td>
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<tr>
<td>Profit carried forward</td>
<td>€ 111,094</td>
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<tr>
<td>Profit of the year</td>
<td>€ 2,454</td>
</tr>
<tr>
<td>Loss of the year</td>
<td>€10,327</td>
</tr>
<tr>
<td>Creditors</td>
<td>€ 190,904</td>
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<tr>
<td>Trade Debts</td>
<td>€101,983</td>
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<tr>
<td>Staff debt</td>
<td>€ 8,987</td>
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<tr>
<td>Transitory accounts</td>
<td>€ 79,974</td>
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<tr>
<td>Total liabilities</td>
<td>€ 346,292</td>
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</tbody>
</table>