ANNUAL REPORT 2016

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INTRODUCTION

It is a true honour for us to present the report on EUFAMI’s activities and achievements in 2016. Our first year as President and Secretary General has been one of consolidation, learning, change, and growth. Important progress has been made towards our three strategic goals of reinvigorating our bond with members, making our impact felt in EU and international circles, and broadening our reach to Eastern Europe. We have also identified key challenges in the year(s) ahead.

In terms of deepening our influence with key international professional and policy stakeholders, the year was framed by two highlights. In January, we presented our Caring for Carers survey to the Carers and Mental Health interest groups at the European Parliament. With co-leader Mental Health Europe, we presented a joint statement to the Governmental Expert group on mental health and the EU Health Policy Forum, attracting the support of nine NGOs by the year’s end. We advocated, among others, for parity of esteem and investment in physical and mental health. Next year’s challenge will be to keep investment in mental health, and health in general, on the EU agenda.

The most ambitious task we set ourselves was to bring our services to families in Central and Eastern Europe where the needs are greatest. We started mapping existing family support organisations and reached out to the European Expert Group on the transition from institutional to Community based care of which we became observing members. In the coming year we will conclude the mapping, and start reaching out to the national organisations identified. The toughest challenge will be to find resources to provide specific support to family carer organisations in Central and Eastern Europe.

Throughout the year, we engaged ourselves to involve and support members more closely – through member visits; through gathering input for EU consultations on the Social Pillar, UNCRPD and Mental Health Compass; and through organizing a member participation day. The highlight of the year, without a doubt, was the Southern Cluster meeting in Porto in November where EUFAMI received the UPA recognition award and held a seminar gathering family members’ personal experiences navigating the complex set of demands put in place by services.

It is at occasions like these that we get to the heart of “our issue: the strong need for improving the lives of families affected by mental ill health” and the role we can play in supporting them. These challenges are plentiful, much progress still needs to be made in respecting human rights, in closing institutions, in organising seamlessly integrated community based care, in involving and supporting family members, and in combating stigma. But together we can turn the frustration with the many obstacles and challenges into positive energy that drives this organisation forward.

After all, 2017 will be a year for celebration. During its first 25 years, EUFAMI created a stronger, better-known public voice for family members. Awareness has grown that family caregivers have special knowledge and experience to contribute to the process of recovery and that involving families can help cut costs, and save lives. Nevertheless, the burden on families remains high across Europe, leading to long-term economic loss and lower quality of care. There are plenty of challenges ahead in the coming 25 years if we want to ensure that the needs of every person affected by mental ill health, and of every loved one, are understood and supported, enabling them to participate in their community in the way they choose. Together, we can take on that challenge!

1The counter stands at 20 endorsements at the time of writing in May 2017.

Miia Männikkö, President
Aagje Ieven, Secretary General
2016 AT A GLANCE

**JANUARY**
- 12 C4C at EP Special Interest Groups Carers + MH and Wellbeing
- 21-22 Co-chair opening session final conference Joint Action MHWB at final conference of Joint Action on MH and Wellbeing
- 27 Value of Treatment of Brain Disorders (VoT) kick-off Meeting

**FEBRUARY**
- 26 EUFAMI board meeting + Officer elections

**MARCH**
- 12-15 C4C at 24th EPA Congress – Towards a Common Language in European Psychiatry
- 17 C4C at Mental Health in France and the World

**APRIL**
- 3-4 PRISM kick-off meeting

**MAY**
- 10 World Mental Health Day – 3rd Online Course on Caring for someone with Schizophrenia
- 20 C4C at Mental Health in Portugal
- 24 World Schizophrenia Day – 2nd Online Course on Caring for someone with schizophrenia
- 28 EUFAMI Annual General Meeting + Board elections + Member Participation Day

**JUNE**
- 14-15 PRISM working meeting on research protocol

**SEPTEMBER**
- 17-20 C4C at 29th ECNP congress
- 30 EUFAMI board meeting

**OCTOBER**
- 6-7 Opening address & concluding panel @ EU Mental Health Compass Forum Conference
- 7 C4C at International Alliance of Carer Organisations
- 8-10 C4C at Excellence in Paediatrics conference

**NOVEMBER**
- 3 C4C at Mental Health in Greece
- 24 EUFAMI Southern Cluster Meeting + PRISM and VoT member seminars
- 25 C4C at ENCONTRAR+SE 10th Anniversary Conference + EUFAMI board meeting
- 26 EUFAMI receives UPA Recognition Award

**DECEMBER**
- 5 Nine NGOs endorse draft Joint Statement on Mental Health at EU Health Policy Forum
- 8-10 C4C at Excellence in Paediatrics conference

**EUFAMI STATS IN 2016**

- **4,218 FANS**
- **2,867,803 IMPRESSIONS**
- **550 NEW FOLLOWERS**

- **2,487 FANS**
- **109,734 IMPRESSIONS**
- **177 NEW FOLLOWERS**

- **3 PEOPLE RETURNED HOME SAFELY**
- **5 EU CONSULTATIONS RESPONDED TO**
- **2240 e-BULLETIN READERS**
- **18 EU and 4 WHO MEETINGS ATTENDED**
- **9* NGOS SUPPORT JOINT STATEMENT ON MENTAL HEALTH**
- **18 CITIES VISITED IN 13 COUNTRIES**

* 20 endorsements at the time of writing in May 2017
Rethink Mental Illness

“In January, the UK Prime Minister Theresa May made her first major speech on domestic policy and promised to right the “burning injustices” that pervaded society. Her area of greatest focus, she continued would be on mental health, and the commitment she wished to see reflected throughout her Government that mental health and physical health should have “parity of esteem”.

MindWise

“WorkWise aims to equip employers and employees with the skills and knowledge to support positive mental well-being in the workplace.”

MèTIS-Europe

MèTIS-Europe organises “Inclusion of youth in difficulty, a challenge for our intervention models and systems” conference on 7 October in Geneva.

HPE Austria

HPE focuses on the anniversaries of 3 regional HPE Austria member organisations: AHA (HPE) Salzburg, 30 years; HPE Lower Austria, 15 years; and HPE Tyrol, 25 years. It also paves the way for its own 40 year anniversary.

BApK

The Federal Association of Relatives of the Mentally Ill

The German association holds an exhibition ‘Blickwinkel’ to raise awareness of mental ill health, a conference on ‘Aggression against Carers’ in Essen and launches a petition to help integrate carers among many other activities.

HUMANA Slovenia

Slovenian member Humana launches charity exhibition of graphic artwork from painter and sculptor Peter Jovanovic 23/8-20/9/2016

Salud Mental España

Queen Letizia of Spain joins President Nel Anxelu González Zapico of Salud Mental España and a delegation of members on 18 October for an awareness raising meeting.

BEDRE PSYKIATRI

BEDRE PSYKIATRI Denmark chief analyst Jens Peter Eckhardt publishes a short article titled “There is no mental health without caregivers” on BJPsych International Blog.

HAFAL

Representatives from Hafal present the ‘Making Sense’ report to the Welsh Government on 19 January. The report makes 10 recommendations to improve Child and Adolescent Mental Health Services (CAMHS) based on the findings.

KINAPSY

A highlight was the Athens event “Translation of Brain Research into Clinical Practice” on 15 March as part of the “Together Under the Umbrella” campaign.

FinFami

The Runner, a new film by The National Family Association and FinFami promotes Mental Health in Finland and takes a stand on the demanding nature of family care.

ŠENT

Completed a series of peer-to-peer training programs with Ozara Slovenija (National Association for Quality of Life).

ENCONTRAR+SE

The Portuguese association ENCONTRAR+SE celebrates its 10th anniversary with an exhibition in Oporto’s Town Hall, the UPA (United to Help) recognition awards ceremony and a charity dinner-party in Pátio das Nações of Palácio da Bolsa in Porto.

SIMILES VL

Similes Vlaanderen focuses on Community Care with so-called ‘Mobile-Teams’ and building its relationship with Belgian Federal and Regional authorities.

KIPRODIPSA

Ongoing advocacy on multiple mental health issues on national and EU level. Organized WMHD event around “Psychological and Mental Health First Aid” theme.

Shine, Supporting People Affected by Mental Ill Health

“Shine continues to provide services to people with mental ill health and their family members, deeming recovery to be a family issue and not just an issue for those with self-experience of mental ill health.”
MEMBER DIRECTORY

at 31 December 2016

STATS

36 members in 23 countries.

EUFAMI has members in 19 of the 28 member countries of the EU.

EUFAMI is a federation of 30 family associations and 6 other mental health associations.

Full members

ARAP – Associazione per la Reforma dell’Assistenza Psichiatrica (Italy)

Ariadne – Verband Ariadne – für die Angehörigen psychisch Kranker (Germany)

Bedre Psykiatri – Landforeningen Pårørende til Sindslidende (Denmark)

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

HPE – Hilfe für Angehörige Psychisch Erkrankter (Austria)

HUMANA – Zdrženje Svojcev pri skrbi za Mentalno Zdravje (Slovenia)

KINAPS – Siblings of People with Mental Health Problems (Greece)

KIPROPS – Advocacy Group for the Mentally Ill (Cyprus)

LSP2GB – Lietuvos Sutrikusios Psichikos Žmonių Globos Bendrija (Lithuania)

LPP – Landsforeningen for Pårørende innen Psykisk helse (Norway)

MHA – Mental Health Association (Malta)

MindWise (N. Ireland)

New Choices (Russia)

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

Rethink – Rethink Mental Illness (England – UK)

Schizophrenieförbundet (Sweden)

Shine – Supporting People Affected by Mental Illness Health and Learning Disabilities Sector (Greece)

HAFAI – for Recovery from Serious Mental Illness (Wales – UK)

METIS Europe (Belgium)

OZARA – Nacionalno Zdrženje za Ľudové Živlenia (Slovenia)

ŠENT – Slovensko Zdrženje za Duševno Zdravje (Slovenia)

Sympathea – Celonárodné Organizace Příbuzných Duševně Nemocných (Czech Republic)

UNASAM – Unione Nazionale delle Associazione per la Salute Mentale (Italy)

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

Unafam – Union Nationale des Amis et Familles de Malades Mentaux (France)

Ypsilon (Netherlands)

Affiliated members

Bedre Psykiatri Ungdom (Denmark)

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

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

METIS Europe (Belgium)

OZARA – Nacionalno Zdrženje za Ľudové Živlenia (Slovenia)

ŠENT – Slovensko Zdrženje za Duševno Zdravje (Slovenia)
STRATEGIC GOAL 1
To expand our membership into Central and Eastern Europe

Key moments in 2016:

- A trainee from the region is recruited to initiate a major mapping exercise of mental health associations in Eastern Europe and to identify those working with families and carers, and other potential partners.
- EUFAMI reaches out to the European Expert Group on the Transition from Institutional to Community Based Care (EEG), a coalition of stakeholders representing people with care or support needs and their families, as well as service providers, public authorities and intergovernmental organisations. They advocate for person centred services and care in the community, with a focus on the East. EUFAMI is accepted as an affiliate member.
- Promotion of our social media was targeted to the new EU member states. By the end of the year, Romania had risen to third place among the countries following EUFAMI on Facebook and Bulgaria had entered the top ten.
STRATEGIC GOAL 2
To involve and support all our members more closely

STATS:

- 8 MEMBER VISITS
- 4 INTERNAL CONSULTATIONS
- 2 NEW MEMBERS JOIN
- 17 MEMBERS ATTEND MEMBER PARTICIPATION DAY
- 40% NEWSLETTER OPEN RATE AMONGST MEMBERS

Key moments in 2016:

- Secretary-General Aagje Ieven visits UNAFAM in Paris (18 March); Labyrint in Perspectief in Utrecht (4 April); Similes in Leuven (4 May); Familiarmente in Lisbon (20 May); Ypsilon in the Hague (7 June); Salud Mental Espana in Madrid (18 October) and ENCONTRAR+SE in Porto (25 November)
- During the Member Participation Day, members views on the future directions of EUFAMI are collected and 17 members work together on 5 potential future projects for EUFAMI (28 May)
- A Southern Cluster meeting takes place for the first time, in Porto, with representatives from Greece, Spain, Portugal, France, Malta and the Azores. They participate in 2 focus groups feeding family perspectives into mental health research and discuss potential synergies for advocacy in the region (24 November)
- EUFAMI receives the UPA Recognition Award that honours people and organisations who play a leading role in the fighting against mental ill health stigma and discrimination. (26 November) at Portuguese member ENCONTRAR+SE's 10th Anniversary Celebrations
STRATEGIC GOAL 3

To deepen our influence with key international and professional organisations and policy makers

STATS

- **5 EU CONSULTATIONS RESPONDED TO**
- **18 EU MEETINGS ATTENDED**
- **4 MEETINGS BY WHO AND AFFILIATES ATTENDED**
- **9 ENDORSEMENTS OF DRAFT JOINT STATEMENT**

Key moments in 2016:

- Joint Meeting of the European Parliament Interest Group on Carers and the Interest Group on Mental Health, Well-being and Brain Disorders launching the results of the Caring for Carers survey by EUFAMI and LUCAS Leuven (12 January 2016)
- EUFAMI President Bert Johnson co-chairs a plenary session Development of community based mental health services at the final conference of the EU Joint Action on Mental Health and Wellbeing (21 and 22 January)
- The WHO Collaborating Centre for research and training in mental health invites us to share the carer’s perspective at “Mental Health in France and the World” (17 March). We further present to policy makers in Portugal (20 May) and Greece (3 Nov) and to psychiatrists (EPA), neurologists (ECNP), informal carers organisations (IACO) and paediatricians (EIP).
- EUFAMI Secretary General, Aagje Ieven, gives an opening address at the EU Mental Health Compass Forum, stressing that access to services comes with access to information for family members, respite care, peer support, and financial support. (6 and 7 October)
- EUFAMI responds to EU consultations on Working Carers, the UN Convention on the Rights of Persons with Disabilities, the EU Mental Health Compass, the European Solidarity Corps and the EU Social Pillar of Rights
- With Mental Health Europe, EUFAMI co-leads the Mental Health Thematic Network on the European Health Policy Platform launched by the Commission on 6 April. At the end of the year, 9 European NGOs have endorsed the Joint Statement on Mental Health in Europe developed through this network (currently 20 signatories).
PROJECTS

PRISM

PRISM aims to find new treatments for the three most common brain disorders in Europe: Alzheimer’s disease, schizophrenia and major depression. It does so by looking at a symptom these three diseases have in common – social withdrawal – and investigating whether there are biological markers for this symptom which new drugs could target to reduce symptoms and improve quality of life. Social withdrawal feeds stigma, which impacts not just patients but entire families. Tackling social withdrawal therefore has enormous potential for positive impact. Committed to supporting families affected by mental illness, the PRISM project is helping EUFAMI to ensure that their views are represented in policy, practice and research. In 2016 we contributed to the research protocol and organised a members’ focus group gathering families’ experiences with symptoms of social withdrawal in schizophrenia.

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

VALUE OF TREATMENT

EUFAMI has contributed to the in-depth research carried out by the European Brain Council (EBC) on the Value of Treatment (VoT) for brain disorders. Analyses demonstrate that there is a considerable treatment gap in Europe, with only about a third of cases receiving the therapy or medication needed. EBC’s VoT project will generate evidence on the socio-economic benefits of health-care interventions through analysis of case studies in order to build towards closing this treatment gap and developing a workable model of care for brain disorders. EUFAMI organised a members’ focus group to document families’ experiences with their loved ones’ “journey” through services to inform the schizophrenia case study.

CARERS ACADEMY

After 2015’s successful first session, the online course "Caring for People with Psychosis and Schizophrenia" developed by King’s College London in collaboration with EUFAMI, was organized twice this year. The second session was launched May 24 to mark World Schizophrenia Day and the third on 10 October 2016 to mark World Mental Health Day. This four-week course explores some of the key issues and questions relevant to a carer who is supporting a relative living with psychosis. It addresses a series of topics aimed at improving understanding of the condition and the impact on the caregiver.

CARING FOR CARERS SURVEY (C4C)

The aim of the Caring for Carers (C4C) survey was to assess the experiences of family caregivers in caring for their relative with severe mental illness from an international perspective, and to highlight the central role they play. The C4C survey was undertaken in 22 countries and received over 1,000 responses, the majority (64%) of which were from those caring for people with schizophrenia/psychosis. In 2016, we launched the survey findings during a meeting at the European Parliament. Throughout the year, C4C was presented to EU and national level policy makers (France, Portugal and Greece), psychiatrists (EPA), neurologists (ECNP), informal carers organisations (IACO) and paediatricians (INEIP). It was disseminated more broadly through our communications strategy.
ANNUAL GENERAL MEETING

The Annual General Meeting is EUFAMI’s highest decision making organ. It is held once a year, approves new members and finances, and elects the Board of Directors. The 2016 assembly took place in our “home town” of Leuven on 28 May and elections were held for one position as Director. André Decraene of Similes Vlaanderen, Belgium was elected.

EUFAMI is governed by its Board of Directors which meets four times a year. The Board sets out the strategic direction of the organisation and oversees the work of the Secretariat. Our Board of Directors are all non-remunerated volunteers, elected by the General meeting.

BOARD OF DIRECTORS

In 2016 the Board of EUFAMI consisted of:

- MIIA MÄNNIKÖ, President, FinFami, Finland
- MARTINE FRAGER-BERLET, Vice President, UNAFAM, France
- PER TORELL, Secretary, Schizofreniförbundet, Sweden
- BERT JOHNSON, Treasurer, Rethink Mental Illness, UK
- CONNIE MAGRO, Officer, Mental Health Association, Malta
- JOHN SAUNDERS, Officer, Shine, Ireland
- KENNETH LIEN STEEN, Officer, Norway
- SPYROS ZORBAS, Officer, Greece
- NADINE FOSSION, Officer, Similes VI, Belgium (retired May 2016)
- ANDRÉ DE CRAENE, Officer, Similes VI, Belgium (elected May 2016)

SECRETARIAT

The Secretariat implements EUFAMI’s strategy and is responsible for the day-to-day running of the organisation. In 2016 the new Secretary General Aagje Ieven took up her position and a rolling internship programme was established to offer recent graduates the opportunity to gain experience in the European policy arena, and to support EUFAMI’s work programme.

ACKNOWLEDGEMENTS

EUFAMI would like to thank the following collaborators for their support in 2016:

De Kleine Prins (Accountants), VRC Audit (Auditors), Untold (Communications), Levuur (Participation consultancy), Paul Nolan (Editing Annual Report 2016), Olalena (Design Annual Report 2016)

ACKNOWLEDGEMENT

In May 2016 Nadine Fossion from Similes Vlaanderen retired as a Board Member. Nadine had been with EUFAMI as a General Meeting Delegate since 1998 and as Board Member and Secretary since 2011. She shared her experiences as a family carer representing EUFAMI on many occasions. We are most thankful to Nadine for her many years of service.
Audited Financial Results 2016

Income in support of EUFAMI's core operations, comprising funds mainly from corporate donors, projects and membership fees, amounted in 2016 to €162,388. This included an extraordinary item of €59,974 received in connection to the Caring for Carers project.

Expenditure for the year amounted to €179,521, the main items being staff and office costs, financial services and general overheads including the Board and General Meetings. The net result was a financial loss of €17,130.

Balance sheet

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<td>Plant, machinery &amp; equipment</td>
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<tr>
<td>Furniture</td>
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<tr>
<td>Other tangible assets</td>
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<td>Current assets</td>
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<td>Trade debtors</td>
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<td>Other amounts receivable</td>
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<td>Cash at bank and in hand</td>
<td>183469</td>
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<td>Transitory accounts</td>
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<td>Total assets</td>
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<td>Capital and reserves</td>
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<td>Allocated funds</td>
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<td>Profit carried forward</td>
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<td>Profit of the year</td>
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<td>Loss of the year</td>
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<td>Creditors</td>
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<td>Staff debts</td>
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<td>Total liabilities</td>
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Income and Expenditure

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<td>EUFAMI Collaborating Partner Programme</td>
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<td>Project funding</td>
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<td>Recovered expenses/Honoraria/Other</td>
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<td>Financial income</td>
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<tr>
<td>Extraordinary income</td>
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<table>
<thead>
<tr>
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<td>Board of Directors</td>
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<td>General Meeting</td>
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<td>Staff Costs</td>
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<td>Write off trade debtors</td>
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<td>Office/insurances/suppliers</td>
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<td>Annual report/Communications</td>
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<td>2859</td>
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<td>Website/promotion/representation</td>
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<td>Finance and legal expenses</td>
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<td>Misc. costs including depreciations</td>
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<td>Project expenses</td>
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<td>Extraordinary charges</td>
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<td>Total Expenditure</td>
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| Profit/Loss                                | -17133   | -54761   |

Detail of Income

1. Core (Collaborating Partner Programme)
   - 2016: 25000
   - 2015: 30000

2. Projects
   - IMI PRISM project: 8154
   - Lundbeck Otsuka alliance Caregiver Initiatives: 20000
   - Lundbeck Caregiver brochure Caring for Two: 3000
   - EBC Value of Treatment: 2250
   - Lundbeck Grant (Family Survey): 0

Total
   - 2016: 33404
   - 2015: 59974
General Commentary

As explained last year by my predecessor as Treasurer John Saunders, EUFAMI continues to face difficulties in obtaining the resources it needs for its everyday working purposes. In this it is in no different position from that of many another charitable organisation.

Over several years past, we have managed to reduce and contain our core expenditure to the range of €160,000 - 180,000 a year while our core income, especially from corporate donors, declined, reaching its lowest point in 2015. Last year’s finance report warned against expecting immediate improvement in 2016 and indeed our income increased only slightly, with the expected consequence of our needing to draw further on our cash reserves, which are now at €82,768.

All year, EUFAMI has been taking steps to halt the decline and reverse this trend. The outlook for 2017 is brighter, with our secured income growing again, though the underlying risks remain (Figure 2).

On the medium to longer term, we must aim to do more than simply balance the accounts, and rebuild our reserves to a more comfortable level, giving us more freedom of action in pursuing our mission. The Board has agreed to the following approach:

- Implementation of the fundraising strategy as a top priority.
- Inclusion of the issues in the risk register which will be kept under review.
- Contingency Planning Group to anticipate possible adverse developments and formulate plans of action.
- Monthly monitoring of income and expenditure to inform that action.
- Re-visiting the prospects for further savings in our core operations.

We shall keep member associations informed of progress throughout the coming year.

Bert Johnson, Treasurer

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

ACCOUNT DETAILS: IBAN BE41 0011 98562110

DONATE NOW

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