

Dear readers,

Here we are with the tenth issue – the fourth of 2013 – of EuCaNews, the Newsletter of EUROCARERS (or EuCa), the European Association Working for Carers! As you will see, this issue is “limited edition” only, not because a few people will see it, but due to its short and “Christmas-related” format. This is mainly due to two reasons: it’s the first time that we’ve tried to set up a fourth issue (normally you get three per year); and secondly, because it’s only just over a month since you received the previous issue (consequently, most of you did not have news or events to share with others within such a short time, and some have asked to postpone their contribution to the next issue, when the “pre-Christmas rush” will be over).

This doesn’t, however, affect the quality of the information you will glean from this Newsletter, which is mainly divided into three sections (going backwards): one dedicated to the news from our members (for the sake of simplicity, this time listed without distinguishing between research and care organisations); one dedicated to EU policy developments (containing an update on the EU carers’ strategy campaign and on the Horizon 2020 programme); and one to news from the executive. In the latter, you will read about some exciting news, a surprise which we hope will represent a real boost for our organisation and for all carers across Europe in the years to come...

*We would also like to thank Henk Bakkerode for his support in preparing the last two issues of the Newsletter. Please keep in mind that **your feedback, comments and ideas for the Newsletter are important** to help us to improve it. So please do not hesitate to send us any contribution relating to your own organisation, experiences or relevant events, which you would like to disseminate to a larger audience interested in caregiving issues in Europe. Please try to keep your contributions as concise as possible (i.e. 1.500 words maximum).*

We wish you a joyful Christmas and a good start in 2014,

Giovanni Lamura
(INRCA, Italy
e-mail: g.lamura@inrca.it)

&

Hilary Arksey
(freelance consultant;
e-mail: hilary.arksey@virgin.net)

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NEWS FROM THE EXECUTIVE COMMITTEE

The results of the call for proposals launched last September by the “Community Programme for Employment and Social Solidarity” (PROGRESS)

By Giovanni Lamura (INRCA, member of the Executive Board)

As many of you might recall, last September Eurocarers submitted a proposal to participate in the call launched by the European Commission’s PROGRESS Programme (<http://ec.europa.eu/social/main.jsp?catId=987&langId=en&callId=383&furtherCalls=yes>), aimed at establishing four-year framework partnership agreements with EU-level NGOs networks working for the promotion of “social inclusion and poverty reduction” or of “microfinance and social enterprise finance”. The period covered by this four-year programme is from 1 January 2014 to 31 December 2017.

In order to participate, Eurocarers – and in the first place, our President Frank Goodwin, supported by an external consultant that Eurocarers decided to hire to support the proposal’s preparation – worked hard last August to draft, internally discuss, finalise and submit to the EU a detailed **four-year programme (2014-17)** of activities to be carried in the field of support to carers in Europe, accompanied by a more specific **annual programme for 2014**. Among the activities included in the proposal, for a total budget of almost 1,8 million Euros in 4 years, the following played a major role:

- contribute to putting in place an EU Carers Strategy by the end of 2015;
- participate in the development of EU policy relevant for carers;
- manage the dissemination of EU-driven policy initiatives to national organisations as well as, vice versa, to encourage participation of national carers organizations in EU policy developments;
- work as a federal-type organisation, expanding the Eurocarers staffing capabilities to support national member organisations in providing a united carers’ voice at EU level;
- analyse existing data and collect new data to support policy-makers’ decision processes;
- carry out research, to include work to establish common data sets on the need for carers and their contribution to the economy and the sustainability of long term health and social care systems;
- investigate the relationship between paid care workers and informal carers, as home care support is an increasing area of employment throughout the EU;
- research and promote an increase in older workers’ employment (aged 55 and over).

In short, Eurocarers’ proposal aimed to convince the EU that Eurocarers is, in the words used by the call itself, one of the relevant “EU-level NGO networks [that] are in a key position to construct coherent approaches with the relevant authorities at EU and national level... by providing expertise and information which are relevant for policy formulation and implementation”. Why does the EU want to support such networks? Because it recognises that “it is essential to secure the quality of the input from both knowledgeable and professional organisations as the engagement and capacity of the national actors is very uneven across Europe. Furthermore, budgetary pressure and reduction of costs resulting from the economic crisis can put at risk the sustainability of funding at all levels. [That’s why] this call is to strengthen the capacity of the EU-level NGO networks to take part in the implementation of the Europe 2020 Strategy and related policy instruments towards the achievement of the European inclusive growth priority”.

The big news is that Eurocarers received on 4 December notification from the EU that our organisation has been selected, and invited to start negotiations to sign an agreement with the EU. Negotiations are currently under way, so that our position should still be very provisional. In any case, we’ll keep you updated on future developments of this thrilling news, which we hope will be positive!!!

EU POLICY DEVELOPMENTS

Update on the Carers' Strategy Campaign

By Christine Marking (advisor to the Executive Board)

As reported in the last newsletter, Eurocarers has embarked on a campaign to ensure the development and implementation of an EU-level strategy to support informal carers. The strategy, entitled 'Enabling Carers to Care', was received favourably by the European Parliament Interest group on Carers, and it was formally launched during a meeting of this Group in October. The proposed strategy is a direct response to a variety of current policy challenges relating to the provision and sustainability of long term care in Europe. It outlines why support for carers is needed, makes the case for the added value of EU-level action, proposes areas where action is most urgently required and sets out tools and ways to address these issues.

What has happened since the launch?

- The Co-chairs of the Interest Group have sent letters (prepared by Eurocarers) to the three most relevant Commissioners – health, social policy and e-health- to call on them for their support and requesting a meeting to discuss this.
- Also, letters (prepared by Eurocarers) have been sent to all MEPs in the Social Policy and Employment Committee, as the support of the European Parliament will be indispensable.
- The strategy has also been presented to a number of EU based organisations, active in the health and social fields, in order to get their support and endorsement; and we are pleased to report that it has been well received.
- We have now incorporated the comments received on the first draft of the Strategy and have a final working document for wider dissemination.
- A one page Manifesto, based on the Strategy, has been developed for use by members during the European Parliament election campaign and for advocacy activities at national level.

What are the next immediate steps?

- We will now work to obtain candidate listings for the Parliamentary elections, in order to best prepare our campaign at national level; we will call on your support for this.
- We will also research EU employers/trade unions and see where we can find hooks for the strategy.
- We will continue contacting other leading EU umbrella organisations for endorsement and support (e.g. European Health management Association, European Union Geriatric Medicine Society, European Disability Forum, European Public Health Alliance, Corporate Social Responsibility Europe etc.).
- And finally, we will organise MEP meetings with the Commissioners, as a follow up to the letters referred to above.

For any questions, please contact Christine marking, cmarking@skynet.be.

European Parliament adopts Horizon 2020

By Christine Marking (advisor to the Executive Board)

On 21 November, MEPs voted in favour of the six reports that together form Horizon 2020, the new Framework programme for research, development, innovation and education. One of the reports (on the European Atomic Energy Community) had already been adopted on 19 November; the five remaining items of the package were approved on 21 November. With a budget of €78.6 billion for the period 2014-2020, Horizon 2020 differs from its predecessor, the Seventh Framework Programme for Research and Technological Development (FP7), in that it merges all EU funding instruments for R&D, innovation and education into one single programme. Built on three pillars – excellent science, industrial leadership and societal challenges - Horizon 2020 maintains funding for fundamental research, but puts emphasis on innovation and research activities that are closer to market applications.

Many MEPs expressed regrets regarding the budget of Horizon 2020: whereas the Commission initially proposed €80 billion, the Parliament had asked for a €100 billion budget. In the end, negotiations on the multiannual financial framework resulted in an amount of €70.2 billion. The Council of Ministers will now formally adopt the different items of the package in the coming weeks.

For more information on all aspects of Horizon2020:

http://ec.europa.eu/research/horizon2020/index_en.cfm

For more information on specific calls concerning carers, see also below the note by Giovanni Lamura on page 9.



NEWS FROM OUR MEMBERS

Final Meeting of the “Renewing Health project”

By Marja Pijl (advisor to the Executive Board)

On 8 October 2013, the last meeting of the Advisory Board of “Renewing Health” took place in Brussels. Previously, our former Executive member Henk Bakkerode had represented Eurocarers within this body, but because he was unable to attend the final meeting I replaced him.

Renewing Health was a large scale project, carried out in nine countries, each represented by one particular region. It started in 2010 and its activities involved totally 7148 patients, in particular those with Diabetes, COPD (Chronic Obstructive Pulmonary Disease) and Chronic Cardiovascular Diseases. Renewing Health tried to make recommendations for a large-scale deployment of telemedicine solutions and their interoperability, thus giving patients more control over their own health. Representatives from some regions presented the results of their work, but not all data from all projects were available, yet. This is because the researchers can only get them published in important journals if the materials have not been published previously. They will become available in the next couple of months.

In spite of the size of the project, the organisations carrying out the project felt they had not been able to demonstrate clearly and with sufficient statistical evidence the effectiveness of telemedicine. Nonetheless, all those who gave reports highlighted improvements that were achieved by telemedicine; only statistical evidence is not yet good enough.

What were some of the most interesting issues which were raised during the meeting?

- There was the question “*for which categories of users will telemedicine be beneficial?*”. It was noted that in some pilots it had been very difficult to recruit enough participants. In Denmark, for instance, no less than 2400 patients had been approached in order to find 266 participants. The Swedish partner reported that some older people had problems with the equipment. It was agreed that not all people can use e-health, such as people with cognitive problems. Several partners insisted that the equipment should be easy to use.
- There were *different results for the three health conditions* that had been monitored. The new method proved considerably more beneficial for diabetes patients than for patients with COPD or heart problems. The Italian partner reported that no clear clinical benefit had been demonstrated for COPD.
- *The consequences for the various categories of care providers* had been included in the research. There had been problems with the involvement of GPs in several projects. This had to do with the structure of the health care system. When GPs receive a fee for services they are often not very interested in taking part in a study which they are not paid for. It was found that the role of nurses had changed, due to the use of telemedicine, but their role had by no means been undermined. **The burden on carers, on the other hand, was**

found to be alleviated. The partner from Italy (Veneto Region) drew our attention to the importance of social care. Several pilots reported that (re)admission to hospital had been reduced and one reported a shorter hospital stay.

- It had been difficult to find good instruments to measure *patient satisfaction*. It seemed that most patients felt comfortable with the new method. The Swedish participants would have liked to have more feedback from the medical staff. There seems to be more loyalty to the healthcare programme among users of e-health.
- *Privacy* had not been an issue that patients had problems with. However, during the discussion it was remarked that in the longer term, patients may find that they are at a disadvantage when their data are available to third parties, for instance when they want to get an insurance, a mortgage or a loan or when they need to get a driving licence.
- It was also noted that *telehealth asks for huge investments*.
- *An important conclusion was that the organisational model of the health and care services is more important than the tools that are being used.*

There was agreement between the partners that randomised controlled trials might not be the best method to demonstrate the value of ICT for the health and care services.

Renewing Health is now finished, but the partners will continue their cooperation in a new project: "United4Health". For further information on the project see: www.RenewingHealth.eu.

Irish Family Carer Research

By Liam O'Sullivan (Care Alliance Ireland)

As part of our service to our member organisations and others with an interest in Family Carer issues, Care Alliance Ireland has collated a database of recent Irish Family Carer Research, which can be consulted under this weblink: http://www.carealliance.ie/publications_currentfamilycarerresearch. The database details over 30 pieces of research that are currently being undertaken or have been undertaken over the past five years.

We are delighted that some significant new primary research is being carried out that will strengthen the development of evidenced based supports and interventions for family carers in Ireland into the future.

Some current and exciting research relates to:

- Family Carers of People with dementia (three studies),
- Carers of people with MS.
- Documenting the contribution of Family Carers in Ireland
- Men as Carers of people with Chronic Illness.

International Workshop on “Networks of local skills in the health-social sectors” on 28 November 2013 in Chioggia (Italy)

By Scuola Centrale Formazione (Central Training School)

On Thursday 28 November 2013, the International Workshop "Networks of Local Skills in the Health-Social Sector: Models in Comparison" took place at the Seminario Vescovile – Associazione Carità Clodinese ONLUS – Chioggia (VE). For many years, the theme of skills recognition has been a focus of attention for the European Commission. The Workshop sought to promote the meeting and the discussion at the international level on the issue of competences in the field of social and health care, with an emphasis on continuous qualification of human resources and certification. The event, organized by “Scuola Centrale Formazione”, the Association “C’ENTRO” and the “Seminario Vescovile – Associazione Carità Clodinese ONLUS”, saw the participation of various experts from five countries: Croatia, Italy, Ireland, Spain and France (see Fig. 1 below). Participants presented experiences of skills networks in the health-social sector, providing an added value and a broader perspective, through the exchange of good practices. The official dinner closing the workshop was used as an opportunity to present to all participants the Association “C’ENTRO”, whose aims are to improve the conditions of action and management of the private lives of those working in the health-social sector with persons with disabilities.

Fig. 1: Participants attending the international workshop on “Networks of local skills in the health-social sectors”



The European Care Foundation (Europejska Fundacja Opieki Polska), Poland

By Iwona Aftyka, Europejska Fundacja Opieki (Poland)

The European Care Foundation (Europejska Fundacja Opieki, Poland) has set up a national helpline for informal carers. The telephone number (+48) 801-044-445 is available from 17:00 to 19:00, on all working week-days (Monday to Friday). Carers can contact our psychologist or leave a message. The aim of the helpline is to offer professional psychological support to carers and to inform them about their rights, benefits, possibilities and where to get help. Our next step will be to organize a support group in Lublin and, in the future, in other cities as well.

A big opportunity for research on carers: “Horizon 2020” is there!

By Giovanni Lamura (INRCA, member of the Executive)

As anticipated above on page 5 by Christine Marking, just a few days ago the biggest EU Research and Innovation programme ever – *Horizon 2020* - has been launched, with nearly €80 billion of funding available over seven years (from 2014 to 2020). Horizon 2020 aims to promote a smart, sustainable and inclusive growth, by funding research and collaboration between scientific institutions, private enterprises and non-profit organisations, to ensure that Europe produces world-class science, removes barriers to innovation and makes it easier for the public and private sectors to work together in delivering innovation. Horizon 2020 is open to everyone, with a simple structure so that participants can focus on what is really important and new projects can start and achieve results faster. The section on *health, demographic change and wellbeing*, in particular, explicitly mentions carers in sub-sections 19, 20 and 25, so it represents the most promising area in which both carers' and research organisations with an interest on carers might want to start preparing research proposals (click [here to open the Work Programme for 2014-15](#)).



About EUROCARERS

EUROCARERS was officially established in Luxembourg in December 2006. Its origin lies in two European networks: Carmen, a network on integrated care and Eurofamcare, a research network on carers of older persons. In the Carmen project researchers, practitioners and policy makers, among them representatives of the carers' movement, found each other and came to the conclusion that it was time for carers to be heard at European level. The Eurofamcare network - consisting of researchers who mapped the situation of carers of older persons and the policy measures developed for this category in the EU and who did quantitative research on the support of carers of older persons in six countries - also diagnosed a strong need for carers to make themselves heard in Europe.

Representatives of the two networks and other interested persons met in Maastricht in 2004 on the initiative of NIZW, the Dutch Institute of Care and Welfare (later reorganised into the two organisations Vilans and Movisie), to discuss the feasibility of establishing a European organisation and decided to go ahead with this task. Christine Marking had written a preparatory paper which helped those who met in Maastricht in formulating decisions about some crucial issues. An interim board was established consisting of: Brigid Barron, President; Patrick Michielsseune, Treasurer; Marja Pijl, Secretary; and the following other members: Judy Triantafillou, Isobel Anderson, Hanneli Döhner, Caroline Glendinning and Henk Nies. Several working groups were formed. Geraldine Visser and Nicoline Tamsma made a report of the meeting. Several meetings took place in the following months and some activities were already developed before EUROCARERS was formally registered in Luxembourg at the end of 2006.

Since then the association has increased remarkably, especially in the last year, and includes now over 60 organisations and several individual associates from all European Member States. Members of the current (2013-14) Executive Committee are: Frank Goodwin (President), Hanneli Döhner (Vice President Carers Associations), Giovanni Lamura (Vice President Research), Licia Boccaletti, Marijke Steenbergen, Helle Lepik and Marja Tuomi. In addition, the Executive is supported by two advisers, Christine Marking and Marja Pijl. For more information on the members of the Executive Committee: http://www.eurocarers.org/about_executive.php.

For more information on the aims and guiding principles of EUROCARERS please go to the link: <http://www.eurocarers.org/about.php>.

EUROCARERS key contacts:

EUROCARERS, 23 Ranelagh Road, Dublin 6, Ireland

Phone: 0034-93-1824913

Email: eurocarers@gmail.com

Website: www.eurocarers.org

EUROCARERS is an NGO & non-profit organisation registered in Luxembourg in 2006 (registration no. F6854).

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