

*Dear readers,*

*Here we are with the first issue of 2014 of EuCaNews, the Newsletter of EUROCARERS (or EuCa), the European Association Working for Carers! In the first section (“News from the Executive”) you will find an update on the PROGRESS funding – which is being granted to Eurocarers for a four-year collaboration programme to support the EU in developing carer-friendly policies and measures – and the programme of the approaching Annual General Meeting in Helsinki on 5-6 June. After the usual update from Christine Marking on EU policy developments (which also includes information on the ongoing campaign for a European Carers Strategy), a rich section on “Carers in Action” provides you the latest news on events and initiatives undertaken by our members. Following the overview on current projects involving Eurocarers and some related news concerning research on carers, finally you will find some short “snippets” of information in the “In brief” section.*

*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 good read and, given the time of the year, a very happy Easter, too,*

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## NEWS FROM THE EXECUTIVE COMMITTEE

### Updates on the EU structural financial support to be received by Eurocarers within the “Community Programme for Employment and Social Solidarity” (PROGRESS)

By Frank Goodwin (President Eurocarers) & Giovanni Lamura (INRCA, member of the Executive Board)

As you might recall from the last Newsletter (No. 10, December 2013), in September Eurocarers submitted a proposal for the call launched by the European Commission’s PROGRESS Programme, aimed at establishing a four-year framework partnership (from 1 January 2014 to 31 December 2017). On 4 December, Eurocarers was notified by the EU that our organisation had been selected and invited, together with other 15 NGOs, to start negotiations to sign an agreement with the EU. Negotiations are now completed and the official start of the project (which is worth a net amount of over 1,3 million EU-funding over the four years) is about to begin.

This has meant a lot of bureaucratic and practical preparation work in the last three months, especially by our President Frank Goodwin, supported by an ad hoc group (made of Christine Marking and Marja Pijl, advisors to the Executive, together with John Dunne, CEO of the Carers Association, Ireland, and Erica Lund, consultant), which the Executive Board decided to set up in a special “PROGRESS-meeting” held on 9 January 2014. Besides revising all necessary documentation for accomplishing the EU-requests during the negotiations (i.e. updating Annual Work Programme, Implementation Plan, Budget etc.), a series of practical steps have been taken (also thanks to useful exchanges with other similar organisations, such as Social Platform, the platform of European social NGOs), in order to solve the following issues:

1. **Office accommodation in Brussels:** we are trying to find an appropriate solution at reasonable prices (any suggestions and hints are welcome!);
2. **Job description of central staff to be hired:** we will check [www.eurobrussels.com](http://www.eurobrussels.com) and talk to other smaller organisations among the 16 chosen for the Progress programme, for the following staff:
  - a. **Administrative staff member:** to manage finances, administrative work (travel expenses, arrangements e.g. conference locations etc; events) and fundraising, we are looking for a medium level staff person (i.e. gross budget for post: approx. €50,000 per year; deductions employee/employer etc.: €18,000 per year, plus health, pension, hospital etc.);
  - b. **Director:** Need to clearly define aspect of role and relationships (given its important role for networking and establishing relationships with key stakeholders in Commission etc). This is a senior post in a small organisation (i.e. gross budget for post: approx. €60,000 per year; deductions, employee, employer etc.: €20,000 per year);
3. **Registering as Non-profit NGO in Brussels:** as well as employer;
4. **Banking in Brussels:** we will need to be careful with timing, and first contacts have been taken with the Bank of Ireland.

## **Welcome to the Annual General Meeting in Helsinki on 5-6 June 2014!**

**By Marja Tuomi (Central Association of Carers in Finland, member of the Executive Board)**

Welcome to Helsinki in June!

This year, the Eurocarers Annual General Meeting (AGM) and Conference will be held in Helsinki, Finland, on June 5 and 6. The topic of the conference is "Caring and working – National carer strategies". Presentations will be given both in a plenary session in the morning and in two parallel sessions in the afternoon, followed by an open discussion. The registration form and the timeline of the conference are available at <http://eurocarers.eventbrite.com>. After completing registration, details on booking arrangements and the venue are provided on an order confirmation. The AGM agenda and the conference programme are reported below, and regularly updated on the website of the Central Association of Carers in Finland at <http://omaishoitajat.fi/central-association-carers-finland>, as well as on Eurocarers' website: <http://www.eurocarers.org/news.php?id=58>. For more information, please contact the event coordinator at [ulla.nissinen@omaishoitajat.fi](mailto:ulla.nissinen@omaishoitajat.fi), tel. +35850 348 5186.

We look forward to meeting you in Helsinki!

### **Annual General Meeting (AGM) of Eurocarers, Helsinki (Finland), 5-6 June 2014**

#### **AGM Agenda and Conference Programme**

**Venue:** WANHA SATAMA, Address: Pikku Satamakatu 3-5, Helsinki; Phone+358-404503160; website: [www.wanhasatama.com](http://www.wanhasatama.com); e-mail: [info@wanhasatama.com](mailto:info@wanhasatama.com).

#### **Annual General Meeting (Thursday 5 June 2014)**

12:00 to 13:00	Registration
13:00 to 15:00	AGM meeting (details will follow, it will include a discussion on issues of poverty and of cut-backs effecting carers)
15:00 to 16:00	Progress project: information & discussion
16:15 to 17:00	INNOVAGE project: information & discussion
17:00 to 17:30	ToYAC project: information & discussion
19:00 to 21:00	Social dinner

## **CONFERENCE “Caring and working: National carer strategies” (Friday 6 June 2014)**

8:00 to 9:00	Registration
9:10 to 9:30	Welcome by moderator of the day (Bettina Sångbom) Frank Goodwin, president, Eurocarers Anneli Kiljunen, MP, chair of Central Association of Carers in Finland
9:40 to 10:00	Opening by Eero Heinäluoma, Speaker of the Finnish Parliament
10:05 to 10:35	National Development Programme for the support of family carers Representative of the Ministry of Social Affairs and Health of Finland
10:40 to 11:15	Employers for Carers / National Strategy for Carers Madeleine Starr, Carers UK, Employers for Carers
11:20 to 11:50	European Parliament Interest Group on Carers: EU Policy Context Sirpa Pietikäinen, MEP, European Parliament Interest Group on Carers
12:00 to 13:00	Lunch
13:15 to 15:45	Two simultaneous sessions (10-15 minute presentations + discussion) (see below)

### **Session I: Reconciling Work and Care**

Jonna Skand	Folkhälsans förbund rf, Finland (Chair)
Elizabeth Hanson	Arbetsgivare för Anhöriga, Sweden
Katherine Wilson	Strategic Manager, Employers for Carers
Kaisa Kauppinen	Research director, University of Helsinki, Finland (Combining employment and informal care-giving – good workplace practices)
Annastiina Vesterinen	Project Manager, Association for Carers in Mikkeli District, Finland (Lamppu Project)
Taina Turtio	CEO, Association for Carers in Pieksämäki, Finland (Lamppu Project)
Tuomas Mänttari	CEO, Association of Social Service Employers, Employer representative

### **Session II: National Carer Strategies**

Sirpa Pietikäinen	MEP (Chair)
Anne-Mari Raassina	Ministry of Social Affairs and Health of Finland (confirmed)
Frank Goodwin	Ireland
Sebastian Fischer	Scotland
Ivar Paimre	Estonia
Laurie Hilsgen	New Zealand

**16.00 to 16.40**      **Summary remarks and closing of the conference**

## EU POLICY DEVELOPMENTS

### Updates on recent EU policy developments

By Christine Marking (advisor to the Executive Board)

#### New EU Health Programme

Health Commissioner Tonio Borg has welcomed the Parliament's positive vote on the third EU health programme 2014-2020. He underlined the aims of the Programme, i.e. to support Member States' action to improve people's health and reduce health inequalities, by promoting health, encouraging innovation in health, increasing the sustainability of health systems and protecting EU citizens from serious cross-border health threats. The Programme is also expected to advance the objectives of the Europe 2020 Strategy by fostering health as an indispensable condition for smart, sustainable and inclusive growth. The new programme focuses on:

- strengthen action to promote health and prevent diseases;
- be better prepared to protect citizens against health emergencies and to coordinate action at European level to address them;
- increase the up-take of innovation in health; and
- improve people's access to medical expertise and information for specific conditions;
- and improve healthcare quality and patient safety.

The call for proposals for Programme funding will be launched by the Consumer, Health and Food Executive Agency (CHAFEA) immediately after the publication of the annual work programme 2014 which can be expected April/early May 2014. The Commission has prepared a document with a number of specific Questions and Answers in relation to the Health Programme, which provides useful information on following items:

- What is the overall aim of the new health programme?
- How does the third health programme compare with the previous two?
- What are the priority objectives of the programme?
- What is the available budget and how will it be distributed?
- How will the programme help Europe emerge stronger from the economic crisis?
- Who will be the main beneficiaries?

*For more information consult the following websites:*

Memo "[Q&A on the third Health Programme 2014-2020](#)"

[http://ec.europa.eu/health/programme/policy/index\\_en.htm](http://ec.europa.eu/health/programme/policy/index_en.htm)

<http://ec.europa.eu/eahc/health/index.html>

#### First meeting of the Commission Patient Safety and Quality of Care Working Group

On 14 February, the Commission Patient Safety and Quality of Care Working Group ([http://ec.europa.eu/health/patient\\_safety/policy/index\\_en.htm](http://ec.europa.eu/health/patient_safety/policy/index_en.htm)) met to develop the EU

patient safety and quality agenda for 2014. This Group brings together representatives from all 28 EU countries, EFTA countries, international organisations and EU bodies. There are two subgroups in this Working Group, one on reporting and learning and another on education and training of healthcare workers. Both subgroups have produced reports which will be published in the spring, along with the European Commission's second implementation report on patient safety. The February meeting also addressed the activities of the European Medicines Agency relating to its work on medication errors and pharmacovigilance (i.e. drug-related surveillance).

The agenda, minutes and presentations of the working group will be published online at [http://ec.europa.eu/health/patient\\_safety/events/index\\_en.htm](http://ec.europa.eu/health/patient_safety/events/index_en.htm)

### **European Semester increasingly focuses on health care**

The so-called European Semester, the cycle of economic and fiscal policy coordination in the EU, has focused on reforming national healthcare systems since 2011, despite the limited power of the EU in this area. Only three EU member states had received country-specific recommendations on healthcare in 2011. A year later, this number had increased to six Member States, and rose to sixteen in 2013. Recommendations are also increasingly detailed. *Next steps are:*

- May 2014: Commission proposes country-specific recommendations for budgetary, economic and social policies.
- June 2014: National ministers to discuss the recommendations.
- July 2014: EU leaders to endorse final recommendations

*For more information:*

<http://www.euractiv.com/health/commission-steps-recommendations-news-533467>  
<http://ec.europa.eu/europe2020/making-it-happen/>

### **Informal MEP discussion on Equity of Access to Quality Healthcare**

On 28 January 2014, MEPs from different political groups and countries held an informal discussion on the issue of unequal access to quality health care in the European countries. The event was hosted by Dr. Andrey Kovatchev (EPP – BUL) and brought together representatives of the Commission, patient organisations, organisations of doctors, nurses and the pharmaceutical industry. The main purpose of the meeting was to reflect on the priorities of the European Parliament for its next mandate and it was agreed that access to healthcare should be a major issue within the EP priorities. The solution to this issue should be sought at European level, despite the limited EU decision-making power in this area. A Written Question was submitted to the Commission on its role in achieving progress in ensuring equal access to quality healthcare for all EU citizens.

For any questions, please contact Christine Marking, [cmarking@skynet.be](mailto:cmarking@skynet.be).

## **Update on the campaign to put in place a European Carers Strategy**

- The Strategy document has been revised, taking into account the comments received from the EU level networks that spoke in the meeting (AGE Platform, the European Patients' Forum, COFACE, the Social Platform and EUFAMI) as well as comments received from Eurocarers members.
- Letters were sent to three Commissioners – Laszlo Andor, Neelie Kroes and Tonio Borg – asking for a meeting with the Interest Group co-chairs. Tonio Borg agreed to meet with us today, and Commissioner Kroes has responded positively, offering a meeting with one of her Directors. a meeting with Commissioner Andor also looks likely.
- The Strategy has been presented in a variety of meetings and events where Eurocarers was invited to speak;
- An EU elections Manifesto has been developed to raise awareness of the need for Strategy amongst candidate, newly elected and re-elected MEPs. This was sent to all members of the Parliament's Women's Committee, Health Committee and Social Affairs Committee.
- The Strategy was sent to all members of the Social Protection Committee as this Committee is currently working on a document on long term care.

## **Final Interest Group on Carers meeting of the current European Parliament mandate**

On 9 April, a final Interest Group on Carers meeting of the current European Parliament mandate will take place in Brussels, with two topics on the agenda:

- an update on the campaign to put in place a European Carers Strategy;
- a discussion on carers and work/life balance.

Health Commissioner Tonio Borg will attend the meeting and present his views on the potential and feasibility of a European Carers Strategy.

For more information please contact Christine Marking, [cmarking@skynet.be](mailto:cmarking@skynet.be).

## CARERS IN ACTION

### **The “Strategic Health Initiative” (SHI) launched by the European Parkinson’s Disease Association (EPDA)**

**By Henk Bakkerode (member of Eurocarers)**

*Introduction: the EPDA Strategic Health Initiative (SHI)*

On 12 February, I attended in London, on behalf of Eurocarers, the launch of the so-called “Strategic Health Initiative” (SHI) of the European Parkinson Disease Association (EPDA). EPDA is the European umbrella organization of all national Parkinson associations in Europe, with which EuCa has cooperated several times in the recent past, for example regarding the Consensus Statement for Carers (CSC).

The EPDA is deeply convinced that more can and should be done to improve awareness and understanding of Parkinson's disease among health care professionals, people with Parkinson's (PwP), policymakers, the media and the general public, as well as to remove barriers that can prevent people with the condition from receiving early treatment and individualised care. By forging an alliance (among others with EuCa), the EPDA intends to challenge mindsets, shift attitudes and make a positive impact on the quality of care for PwP.

Therefore, the EPDA formed a PD SHI European Task force that includes representatives from European umbrella organizations, e.g. EuCa. The SHI is being supported by treatment company AbbVie which brings in its expertise in Parkinson's as well as its experience of working on similar multi-stakeholder initiatives in other disease areas. The need for such a project was confirmed by focus groups which had been organized from across Europe. The reason that Eurocarers was invited to join the Task force are our Guiding Principles, Aims and Mission Statement which are indeed close to the Parkinson's EPDA's.

*Proposed activities*

During our meeting, much was discussed on Parkinson's SHI Vision: “To ensure comprehensive and individualised care management, for all PwP throughout the disease progression, and to enable all PwP to live a full life”. The vision should be realised with three strategies:

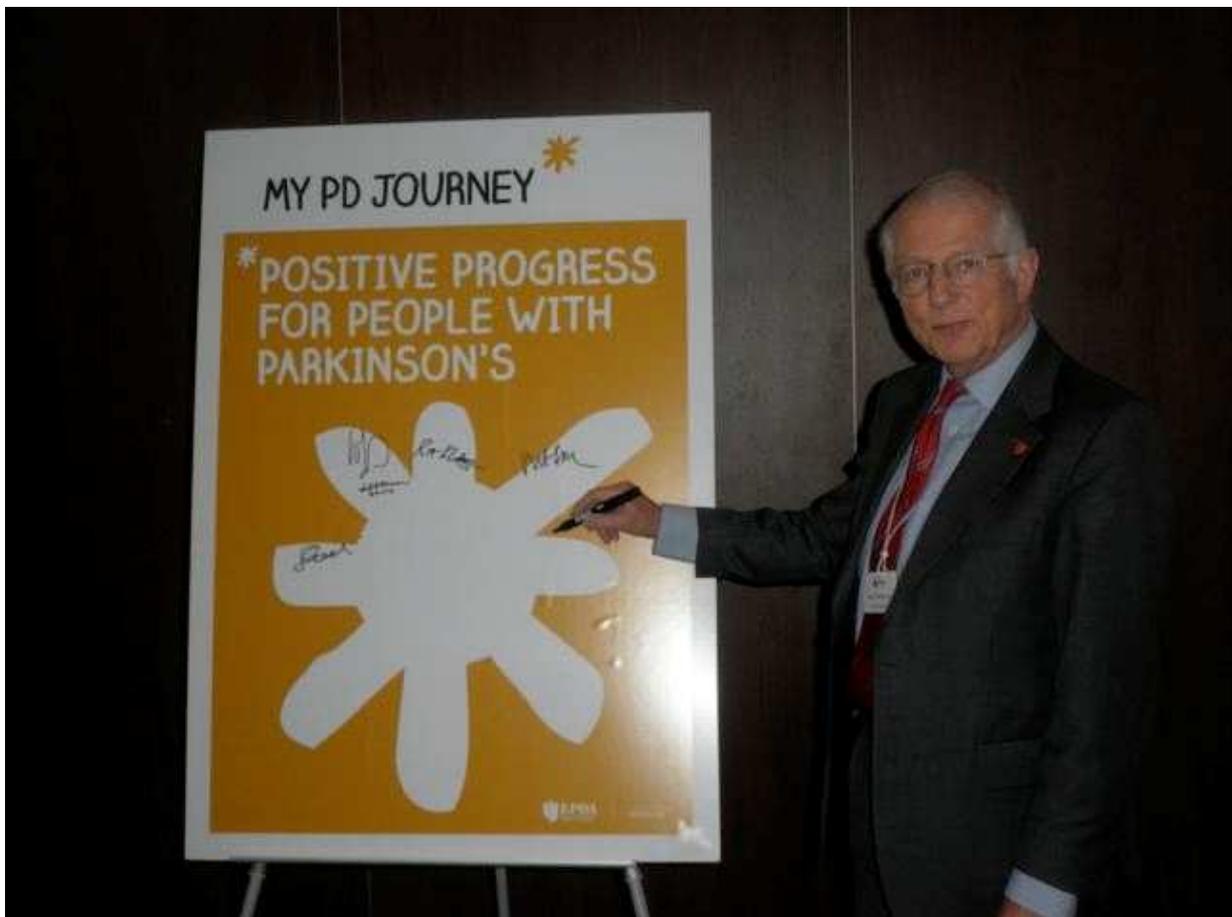
1. Understand the different hurdles to treat progression of Parkinson's; in this framework an Inventory was proposed, comparing the different National PwP pathways (the PwP and HC journey) in key countries, in order to identify key barriers within the health care system as well as what works well. This would help contribute towards a Best Practices Repository. This is a proposed first project that would be delivered by the PD SHI EU Coalition;
2. Tailored care for PwP throughout their journey. Here the proposed activities are: “Prove the value of MultiDisciplinary Teams” (MDTs); and: “Move beyond the “stages” of PD to an individual approach”;

3. Implement solutions that contribute to comprehensive management of Parkinson's, through activities such as: "Validate Measurements for non-motor and motor-systems"; and: "Identify tools that can strengthen HCP - PwP - caregiver interaction".

It is clear that much has still to be elaborated by the team. Two items to be mentioned still here are the following:

- the development of messaging and visual identity. The EPDA chose for: "My PD Journey; positive progress for PwP";
- in a later phase, also on national level, coalitions of all stakeholders will have to be organized (by the national Parkinson's organizations, with partners).

**Fig. 1: Henk Bakkerode participating on behalf of Eurocarers at the launch of the "Strategic Health Initiative" (SHI) of the European Parkinson Disease Association (EPDA) in London on 12 February 2014**



#### *Governance structure*

The following structure is foreseen:

- the PD SHI European Strategic Committee (in which Eurocarers is a member, with several other European Associations). This will provide ongoing strategic oversight and ensure effective implementation of the work program;

- Parkinson's Specialist Panel (eg. neurologists, Parkinson's specialists); this will support project implementation and provide oversight;
- PD SHI European Working Groups, with people who will carry the burden of workload, to be established as required, but to include necessary specialists (eg carers). These will scope, create and implement project plans by their activities;
- PD SHI European Secretariat (with a project manager, still to be appointed by EPDA). This will ensure the smooth delivery of the SHI (coordinating, facilitating, reporting, etc.). And will liaise with the EPDA - MEP network.

### *EuCa's role*

For EPDA, the commitment of EuCa is very important, because the patients (also the PwP, but all patients with neuro-degenerative diseases) have a lot interests in common, on which we should cooperate. Our participation in the project is highly appreciated. It will not bring an immense workload, but as a representative I will participate in this structure in defining mission, targets and in decision making as a member of the Strategic Committee. Therefore I signed on the spot the so-called "Charter for the structure and governance of PD SHI Europe" (with all sorts of formalities, but without any financial responsibility or effect).

The report of the meeting will be written up and circulated to all participants next week. Any member of EuCa who might be interested in further details can of course receive this and other documents.

For further information please look also at the latest issue of the EPDA's Newsletter: <http://www.epda.eu.com/en/resources/epda-plus/issues/issue-24/>.

## **Nationwide Survey of Carers of people with Neurological conditions**

**By Liam O'Sullivan (Care Alliance, Ireland)**

As part of the Brain Awareness Week 2014, a survey of those affected by neurological conditions and family carers was undertaken and has been recently published. In collaboration with The Neurological Alliance of Ireland, Care Alliance Ireland issued a joint press release, highlighting the findings as they pertain to family carers.

To view the press statement, please consult the weblink: [http://www.carealliance.ie/userfiles/file/National\\_Survey\\_Highlights\\_Impact\\_of\\_Cutbacks\\_on\\_Family\\_Carers\\_Final\\_120314.pdf](http://www.carealliance.ie/userfiles/file/National_Survey_Highlights_Impact_of_Cutbacks_on_Family_Carers_Final_120314.pdf). The full report is available now to view on the Care Alliance Ireland's website [http://www.carealliance.ie/userfiles/file/NAI\\_Survey\\_A4\\_1\\_.pdf](http://www.carealliance.ie/userfiles/file/NAI_Survey_A4_1_.pdf).

For other news, resource and details of upcoming events of this organisation, please visit their home page <http://www.carealliance.ie/>.

## **Joint workshop of representatives of the Programme on Ambient Assisted Living (AAL) and of the Joint Programme on Neuro-Degenerative Diseases (JPND)**

**By Henk Bakkerode (member of Eurocarers, Netherlands)**

On 27 January a joint workshop was organized here in Amsterdam, bringing together representatives of two EU-funded programs: the Joint Program on Neuro-Degenerative Diseases (JPND) and the Program on Ambient Assisted Living (AAL). The meeting was hosted by the Dutch Ministry of Health and Human Services, and some 50 persons were present from all over Europe. Plenary and sub-group discussions were held on the main topics:

- A. User needs (how to identify and meet them in the programs);
- B. Marketability aspects;
- C. Setting standards.

Below, the main items discussed in the three subgroups are briefly summarised.

**Working group A** focussed on the needs and wishes of the end-users with dementia and on methods of user involvement in designing solutions. Informal carers are also important end users here. Also, ethical issues regarding ICT/technology and involvement of patients were addressed. The discussion was focussed on questions like: what do you know and did you find out in your research about these needs and wishes? How can these needs and wishes for care and support of people with ND be assessed (i.e. what are the suitable and available methods)? What can be the role of ICT/smart technology (as being developed in AAL) in JPND research about prevention, early diagnosis, treatment and care and support for people with ND and their carers? What is the difference between researchers and health care workers? What are the key recommended actions that need to be taken by both parties (AAL and JPND)?

**Working group B** focussed on how to develop markets for / address barriers to the uptake of ND-relevant ICT technology in health care. Discussions included industry access mechanisms, sustainability issues, replication of innovative measures across regional, national and EU-levels. Issues addressed were: what are the issues that are preventing the development of markets or restricting uptake? What are your ideas, experiments and solutions? Are there possible enabling incentives or interventions, and what key actions need to be recommended?

**Working group C** focussed on how to set standards for evaluating measures and testing in different cultures on the basis of the experiences of different projects with the local, real-life context of patients. At stake were also users' involvement mechanisms, acceptability, experimental methodology and results. More specific questions were: what are the most relevant standards and interoperability requirements in ND application in terms of non-technical items (standardization of design, of installation, of usability etc.)? What can a system developer do to implement standards in terms of non-technical items? Which instruments and values are in this case critical for the patient at home? What about the privacy aspects?

As you can see, many questions were raised, not all of which could be answered. The discussion will be continued. Responsible authorities in both programs will cooperate more closely in the near future.

For more information, see the websites of both programs: [www.jpnd.eu](http://www.jpnd.eu) and [www.aal-europe.eu](http://www.aal-europe.eu).

## **InterRAI Single Assessment Tool (SAT) National Implementation Project (Ireland) and Carer Needs Assessment Development**

**By Clare Duffy (Social Policy Manager at The Carers Association, Ireland)**

In 2010, Ireland's Health Services (HSE) set up a National Single Assessment Tool Working Group with the task of selecting, piloting and recommending a Single Assessment Tool (SAT) to address Irish health and social care policy requirements for a national standardised needs assessment and to better support integrated service delivery and best practice in older persons care. Following an extensive evaluation and stakeholder consultation process, it was agreed that a computerised assessment tool would be preferable and three assessment tools were shortlisted. Selection criteria were agreed and a decision-matrix approach using a quantitative technique was employed, to rank each tool against the multi-dimensional options of the set of criteria. This resulted in the InterRAI suite of assessment tools being chosen as the most suitable instrument.

The InterRAI is a suite of comprehensive geriatric assessment tools designed for various health care settings. The first InterRAI instrument was developed in the United States to assess nursing home residents. Subsequently, a network of international clinicians and researchers set up the InterRAI consortium, as a not for profit collaborative organisation to apply InterRAI assessments in other countries and to develop other multi-disciplinary assessment tools to assess the wide range of health and social care needs of older people. By using a common language of assessment, the InterRAI system facilitates information sharing in a consistent and transferable way between health and social service agencies. Aggregated data can be used to support outcome measurement, resource allocation, service planning, quality measurement, research and policy decision-making. Currently, the InterRAI suite consists of 14 instruments available for use across a range of settings and is used in over 30 countries.

### *Carer Needs Assessment*

The Association has worked with the HSE since 2010 in the selection and piloting of a suitable SAT, and more importantly have lobbied for the SAT to include a Carer Needs Assessment. In 2012, the HSE finally gave a commitment as part of their national implementation plans to develop an InterRAI *Carer Needs Assessment Supplement* in partnership with InterRAI consortium, in order to fully support family carers who are central to enabling older people to remain at home. This will be the first time that the InterRAI consortium has developed a Carer Needs Assessment and so the Irish assessment may eventually be rolled out in countries across the world.

The HSE have established a Carer Needs Assessment Working Group to facilitate the development and implementation of the national *Carer Needs Assessment Supplement*, based on

interRAI standards for Instruments and Systems Development. This Carer Needs Assessment Working Group (on which the Carers Association is represented) includes both Irish and interRAI members who will lead on the development and testing of a Carer Needs Assessment tool for national and international use. In an effort to ensure that the views expressed are reflective of all caring sector organisations, the Association has established a separate Carers Reference Group (consisting of representatives from Caring for Carers, Cross Care, Care Alliance Ireland and Rehab Care) who have the opportunity to provide feedback to the Carer Needs Assessment Working Group through the Association's representative.

The HSE plan to begin pilot testing the Carer Needs Assessment in June 2014, which means there is a considerable amount of work to be done beforehand, including agreeing the content of the actual Carer Needs Assessment itself. For the pilot study to be valid, the HSE must provide a Single Assessment to 200 older persons and a Carer Needs Assessment to their 200 carers (i.e. 400 people in total). The HSE have secured funding for Research Nurses to undertake these assessments (most probably in the homes of the older person/carer) and have asked the Carers Association for our assistance in sourcing older people and carers to participate in the pilot study. As it will be necessary to achieve ethics approval for the pilot study, the HSE have also asked the Association to work with them in preparing the requisite ethics proposals.

Projected key Milestones of the overall SAT Project and completion timeframes:

- Procurement of software and other resources (Q1-Q3 2013);
- Refinement of InterRAI tools for use in Ireland (creation of Irish Editions) (Q1-Q3 2013);
- Development/ piloting of Carer Needs Assessment (Q2 2013-Q4 2015);
- Implementation (2014- 2016) (circa 5500 healthcare personnel trained in use of the tools);
- 'Close-Out' (and Plan Further Phases if Agreed) (2017).

For further information on the SAT or the Carers Needs Assessment please contact Clare Duffy: [cduffy@carersireland.com](mailto:cduffy@carersireland.com).

## **Consultation launched by the Scottish government on new carer legislation**

### **By Sebastian Fischer (Vocal – Voice of Carers across Lothian, Scotland)**

The Scottish Government launched recently a consultation on new proposals for carer legislation in Scotland, following a long campaign by carer organisations for improved carer rights (we called it 'From Recognition to Rights'). At the Carers Parliament on 1 October 2013 the First Minister for Scotland, Alex Salmond MSP, announced the Scottish Government's intention to bring forward legislation to support carers and young carers. Now the consultation paper – 'Carers Legislation / Consultation on Proposals / January 2014' - sets out proposals to improve outcomes for carers and young carers across Scotland and views on those proposals are welcome. The full consultation paper and response form can be found at: <http://www.scotland.gov.uk/Publications/2014/01/4757>. Responses are to be returned by 16 April 2014. This may serve as inspiration to campaigns in other countries. For more information please contact Sebastian Fischer at VOCAL - Voice of Carers Across Lothian, e-mail: [sfischer@vocal.org.uk](mailto:sfischer@vocal.org.uk); website: [www.vocal.org.uk](http://www.vocal.org.uk)

## RESEARCH ON THE MOVE

### Overview of the projects in which EUROCARERS is currently involved

**By Giovanni Lamura (EUROCARERS Vice-President for Research, INRCA, Italy)**

The table below provides an overview of the main projects in which EUROCARERS is currently involved (distinguished in two groups: those with a budget allocated to Eurocarers, and those without a budget, i.e. in which Eurocarers plays mainly an advisory role). As you will see, the main news is represented by the PROGRESS project, whose remarkable funding should allow our organisation to be strengthened in achieving our aims at EU level within the Europe 2020 objectives (see also update on this on page 3). The AIDA (see also Fig. 2 below, referring to one of the last project's meetings) and CARICT-PUBL projects are about to be completed, while the INNOVAGE project is now entering into the piloting phase of the web-based platform of support services for carers, to be completed by next June.

<b>Updated overview of projects in which EUROCARERS is currently involved</b>							
Title	Duration	Funding programme	EuCa contact person	Budget to EuCa (Euros)	EuCa co-funding	Dedicated staff	Focus
1	2	4	5	6	7	8	10
<b>Projects with budget</b>							
<b>AIDA</b>	2.2012 - 11.2013	PROGRESS	Licia Boccaletti	51.790	12.930	Martha Mackay	Integration of social and health care services
<b>CARICT-PUBL</b>	9.12-3.2014	IPTS	Frank Goodwin	2.450	None	none	ICT-based services for informal carers
<b>INNOVAGE</b>	12.2012 - 11.2015	FP7-Health	Hanneli Döhner	201.960	48.600	Areti Efthymiou	ICT-based services for informal carers
<b>PROGRESS</b>	1.1.2014-31.12.2017	PROGRESS	Frank Goodwin	1.579.000	25%	To be hired	Strengthening EuCa's capacity to implement the Europe 2020 Strategy
<b>Projects without budget</b>							
<b>Icare4EU</b>	3.2013 - 2.2015	EAHC - Health Programme	Marja Pijl	Travel costs only	None	None	Care for people with chronic conditions (Advisory Board only)
<b>More Years Better Lives</b>	2011	FP7	To be decided	Travel costs only	none	none	Coordination of initiatives in the field of demographic change (Advisory Board only)
<b>SMARTCARE</b>	3.2013 - 2.2015	ICT PSP – CIP	Marja Pijl	Travel costs only	none	volunteers	ICT services for integrated care

**Fig. 2: Madeleine Starr (Carers UK), Marja Pijl (advisor to Eurocarers' Executive Board) and Licia Boccaletti (Anziani e non solo, Member of Executive Board) during the AIDA project meeting held in Brussels on 15 October 2013**



## **The EU-funded project “Robolaw: Regulating emerging robotic technologies in Europe”**

**By Henk Bakkerode (member of Eurocarers, Netherlands)**

Recently, Eurocarers was asked to participate, as a potential stakeholder, in the European-funded research project called “Robolaw”: "Regulating Emerging Robotic Technologies in Europe: Robotics Facing Law and Ethics. The main objective of this project is to elaborate a series of "Guidelines on regulating emerging robotic technologies", to be delivered to the EU Commission in Spring 2014. The Consortium is formed by University Institutions from Pisa (Italy), Tilburg (Netherlands), Reading (UK) and Munich (Germany). Funding comes from the Framework Program 7, "Science in society".

The results will help the Commission to decide how best to intervene and regulate emerging robotic technologies, ranging from driverless vehicles and household devices, to robots for surgery and prostheses, as well as industrial robots and softbots. Questions emerge like: If, how and when to regulate, with which rules? These questions seem to be

crucial for the responsible proliferation of useful robotic technologies and, in some cases, the very development of a market for such applications.

EuCa was asked to fill in a questionnaire concerning the field of robotics and our experience with this. No other commitment or involvement in this phase of developments was asked for. Many of the questions concentrated upon personal experiences of patents with these technologies, therefore many questions were not directly relevant to us. These questions would have been more relevant for individual care institutions with daily experiences in this field.

Nevertheless this seems to me an important development: what about ethical values privacy, loneliness and liabilities in these respects? These questions will also be relevant to informal carers using technologies in the home situation. So, although our cooperation was asked only this time and incidentally, it will be interesting to follow the results and recommendations of this Consortium to the Commission, because the planned legal framework for robotics should certainly be guided by carers' interests.

To view more information, go to the project's website: [www.robolaw.eu](http://www.robolaw.eu).

**First Newsletter of the ENS4Care project:** Eurocarers is partner of the ENS4Care project, which has been funded within the call of the *ICT-PSP work programme 2013* for a Thematic Network on “**Clinical practice guidelines for eHealth services**”, focussing on nursing and social care workers and aiming at producing evidence-based guidelines in this field. The first quarterly eNewsletter from this project can now be found on the project's website: <http://www.ens4care.eu/latest-news/ens4care-first-quarterly-enevletter>.

**Social networking among older people:** an in-depth review on how older people use web-based social networks has been recently published, showing how these tools allow them to keep in touch with their children and grandchildren, i.e. their potential caregivers in case of need. The main benefit of using social networking sites for older adults is to enter in an intergenerational communication with younger family members (in particular with children and grandchildren), that is appreciated by both sides. Barriers that might prevent this from happening are privacy concerns, technical difficulties and the fact that current web design does not take the needs of older users sufficiently into account. To download or have a look at this scientific publication please consult the following weblink: [http://www.cclm.unibe.ch/unibe/philhuman/cclm/content/e200922/e200932/e273258/linkliste273259/Nefetal.-2013-Socialnetworkingsitesandolderusersasystem\\_ger.pdf](http://www.cclm.unibe.ch/unibe/philhuman/cclm/content/e200922/e200932/e273258/linkliste273259/Nefetal.-2013-Socialnetworkingsitesandolderusersasystem_ger.pdf).

## IN BRIEF

**“Does your carer take sugar?”**: in this interesting paper Luke Clemens, Professor at the Cardiff Law School and longstanding expert in the field of disability and caregiving issues, analyses the struggle waged by unpaid carers for recognition as “human rights holders”. He will be attending the next IACO (International Association of Carers Organisations) meeting, to be held in Helsinki in June 2014. You can download this paper free under the weblink: [http://www.carersnsw.org.au/Assets/Files/Does\\_your\\_carer\\_take\\_sugar\\_Oct2013.pdf](http://www.carersnsw.org.au/Assets/Files/Does_your_carer_take_sugar_Oct2013.pdf).

### **Launch of new Europe-wide network on innovation for age-friendly environments:**

According to the World Health Organisation (WHO), physical and social environments are key determinants of whether people can remain healthy, independent and autonomous long into their old age. Creating age-friendly environments is therefore one of the most effective approaches to respond to demographic change. To support this approach, **the AFE-INNOVNET thematic network on innovation for age-friendly environments (AFE)** kicked off on 14 March with the support of the European CIP ICT PSP Programme and will run for two years. The **four overarching goals** of the AFE-INNOVNET thematic network are to: 1) **mobilise a wide range of local and regional authorities and other stakeholders** – industries, research centres, universities, civil society organizations – to link up, benefit from each other’s experiences and work together to promote initiatives on age-friendly environments across Europe; 2) **develop methodologies** to help local and regional authorities assess the socioeconomic impact of age-friendly environments and the benefits of involving older people in the co-production of age-friendly environments solutions; 3) develop a **repository of notable and replicable practices** in innovative solutions for age-friendly environments with associated socio-economic evidence; 4) launch an **EU Covenant on Demographic Change** to create the necessary political and technical framework to bring together in a more formal and long-term structure local and regional authorities – and other stakeholders - across Europe, using the model of the existing Covenant of Mayors on sustainable energy. The consortium is composed of **28** partners from 16 EU countries and includes 12 cities and 5 regions. **The project will open up to new partners in April. If you are interested**, please visit the project [website](#), or contact Julia Wadoux, AFE-INNOVNET Coordinator, at [julia.wadoux@age-platform.eu](mailto:julia.wadoux@age-platform.eu). Tel.: +32.2.280.14.70.

**A guideline for caregivers of people with rare diseases:** The Caregiver Action Network (CAN) recently announced the launch of [www.RareCaregivers.org](http://www.RareCaregivers.org), a comprehensive online guide that addresses the distinct needs of family caregivers of loved ones with rare diseases. “As a caregiver of a loved one with a rare disease, you can feel overwhelmed and hardly know where to start. That’s not surprising. Caregivers in the rare disease community face exceptional challenges,” said John Schall, CEO of the Caregiver Action Network. “That’s why we launched this website to provide free practical help and advice,” Schall said. To read the press release, please consult the following weblink: [http://caregiveraction.org/news/?news\\_id=65](http://caregiveraction.org/news/?news_id=65).

**Global Forum on Incontinence (GFI):** The 5<sup>th</sup> GFI will take place in Madrid, 8-9 April 2014. The GFI is a platform for education and debate about the impact of incontinence on individuals, caregivers and society. The objective is to suggest principles for a better

organization of continence care. Policy makers, health and social care providers, NGOs and medical experts will gather to listen to presentations in the area of continence care, exchange views and explore what opportunities there are to achieve sustainable quality continence care. The conference will foster consensus around the way forward for better continence care that can be implemented in different local health and social care environments. Eurocarers will be represented at this Forum by Giovanni Lamura, who has been asked to contribute to a plenary panel session. This will aim to reflect on how patients with incontinence and caregivers experience today's service delivery and face the related challenges, but also on what policy-makers should do in order to address such challenges and improve the way continence care services are organized. For more information on the GFI, please go to the dedicated link: [www.gfiforum.com](http://www.gfiforum.com).

**“Carer role should be a major public health concern”: reactions to the findings of a study on carers of children with disorders:** On 7 February 2014, the Irish Times published an article underlining that “carer role should be a major public health concern”. The article, written by Kitty Holland, reported about the reactions of the Irish Carers Association to a recent study on “Growing up in Ireland” from the Centre of Social Issues at the University of Limerick, focused on carers of children suffering from different types of disorders. This research report found the high levels of depression among these carers was partly due to difficulties managing these children with at-times severe behavioural difficulties, with the health and well-being of the children taking precedence over their own well-being. Catherine Cox, spokeswoman for the Carers Association, said that given the impact of caring on care-givers, “it is in everyone’s best interest to care for the carer and put in place systems that consider the carer’s mental and physical health needs as a priority.” For more information: <http://www.irishtimes.com/news/social-affairs/campaigners-argue-that-caring-should-be-classified-as-public-health-concern-1.1682478>

**Retirement of Prof. Caroline Glendinning, one of the first supporters of Eurocarers:** some of our readers may know Prof. Caroline Glendinning, longstanding member of the University of York (UK), through her involvement in the past with Eurocarers’ activities, especially in the first “hard” years after the association was established. Caroline is now hanging up her social policy hat and retiring at the end of April 2014. She has been influential in the social policy world for many years and has worked with countless colleagues, both nationally and internationally throughout her career. We would like to wish Caroline all the best in this new phase of her life!

## 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](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>.*

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