Carers of Persons with Heart Failure

A Four Nation Study

Heart failure caregivers face critical gaps in resources and support, new international study shows.

The International Alliance of Carer Organizations releases a first-of-its-kind four nation study on heart failure caring.

Adelaide, South Australia, Australia (PRWEB) October 03, 2017 – The International Alliance of Carer Organizations (IACO), supported by Novartis, has released a first-of-its-kind global study examining the role and impact of heart failure caregiving. Presented at the 7th International Carers Conference in Adelaide, Australia, the Carers of Persons with Heart Failure study analyzed data collected from more than 500 heart failure carers in Australia, Canada, the United Kingdom, and the United States to determine the key challenges that they face.

The research builds on existing evidence of the positive influence of caregiving on heart failure outcomes, including improvements in health-related quality of life, reduced rates of hospitalizations, and improved survival for the person with heart failure when the carer receives adequate support. Despite this positive influence, many carers face a significant unmet need for resources and support, according to the new data. Key findings include:

• While 70% percent of carers helped with medical and nursing tasks such as managing medications or monitoring symptoms, only one in five (19%) say they were prepared for these tasks by health care professionals.

• More than half of carers (53%) reported that they felt like they had no control of the heart failure condition.

• Caring for someone with heart failure was found to have a significant personal impact on caregivers, as many carers noted that they had to take an early retirement or quit work in order to provide care.

• One-third of carers found it difficult to support the person with heart failure with activities of daily living, such as bathing or toileting, and instrumental activities of daily living, such as managing finances and housework.

• On average, heart failure caregivers scored their quality of life as six (6.0) on the ladder of life from 0-10.

“Receiving adequate support from a caregiver is an important factor in the health-related quality of life of persons with heart failure, but – as these data show – caregivers themselves don’t have adequate support to help them play this important role while minimizing impact on their own well-being,” said David Palacios, Head of Global Patient Relations, Novartis Pharmaceuticals. “This study provides an important insight into the role and impact of heart failure caregiving, and underlines that better support for caregivers is an important way we can improve overall health outcomes in this space.”

“Carers in general, and heart failure carers in particular, are an under-recognized group,” said Rick Greene, Executive Advisor, International Alliance of Carer Organizations. “We hope this new study can bring to light common challenges across nations where heart failure carers need support and the strategies needed to improve quality of life outcomes for those in a caregiving role. Supporting carers is a critical step in improving outcomes for the person with heart failure.”
In response to the study findings, IACO outlined several key policy recommendations to help address the need for improved support and levels of resources available to caregivers in heart failure. Highlights include:

- Ensuring health care professionals engage, assess and support caregivers as members of the heart failure care team, and acknowledge their critical role in the implementation of the treatment plan for people with heart failure;

- Improving government information and increasing awareness and understanding of heart failure caregiving and the challenges faced; and

- Providing caregivers with resources and support to prepare for their role and navigate the workplace, health system and available support services.

The study was conducted in Australia, Canada, the United Kingdom and the United States, and IACO collaborated with carer and patient organizations in the four countries. The leading organizations were: Carers Australia, Carers Canada, Carers UK, National Alliance for Caregiving (US), WomenHeart: The National Coalition for Women with Heart Disease (US), Pumping Marvellous (UK), Canadian Home Care Association, The Heart and Stroke Foundation of Canada, and Heart Support-Australia Ltd.

For more information and to download the study, visit www.internationalcarers.org.

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**About IACO**

The International Alliance of Carer Organizations (IACO) is a global coalition of 15 member nations committed to building a global understanding and respect for the vital role of family carers. Recognized as an official NGO by the United Nations, each IACO member country is represented by a nationally-renowned carer organization. The coalition meets annually to share best practices, identify global issues, and advocate for family carers. To learn more, visit www.internationalcarers.org.

**About Novartis**

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