

Research Study on Carers of Persons with Heart Failure

Dear Carer:

The International Alliance of Carer Organizations (IACO) has received funding from Novartis to conduct a four nation study of carers of persons with heart failure. The four nations are the United States, Canada, United Kingdom and Australia. In each of these nations, our carer member is collaborating with a heart patient advocacy organization on this important study.

We know that your time is extremely busy assisting your loved one and balancing work and family obligations. Therefore, we will limit the number of questions we will be asking you. We are seeking friends and family members who care for a person with heart failure to complete this brief survey on their experiences. The on-line survey should take you approximately 10 minutes to complete. **Please note that all responses will be confidential and no identifying information will be collected.**

IACO defines a family carer as an unpaid individual who is involved in the care of a person with heart failure. This can be a spouse, partner, parent, another family member or close friend. For the purpose of this survey, heart failure is a clinical syndrome in which a person may experience symptoms such as breathing difficulties, gathering of fluid in the lower limbs or stomach and extreme lethargy or tiredness. When the heart either fails to pump efficiently or it fails to relax and fill efficiently, this is heart failure.¹

We will be asking a series of questions about the impact of heart failure on you and the person for whom you provide care. We are particularly interested in how caring for a person with heart failure affects your employment, finances, health, and social life. We will also ask you questions regarding your experience with health care providers.

The information that we collect will be published in a report in September 2017 and posted on IACO's website, which is www.internationalcarers.org/research-study-on-carers-of-persons-with-heart-failure/. We anticipate distributing the report to key policymakers in the four nations and anticipate that the findings will be used by them to introduce legislation, modify regulations and possible to provide support services to carers of persons with heart failure.

¹ Adapted from Pumping Marvelous (2016). *My Marvelous Guide to Heart Failure*. Preston: United Kingdom.

Should you have any questions, please feel free to email me at rickgreene@caregiving.org . We thank you in advance for your assistance.

Regards,
Rick Greene, MSW
Executive Advisor
International Alliance of Carer Organizations