National Alliance for Caregiving

Advancing Family Caregiving through Research, Innovation & Advocacy

U.S. Senate Special Committee on Aging

Roundtable Meeting

"Harnessing the Power of Telehealth: Promises and Challenges?"

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Good morning. My name is Gail Gibson Hunt, and I am the founder, President and Chief Executive Officer of the National Alliance for Caregiving ("Alliance"). As part of this role, I serve as a member of the governing board of the Patient-Centered Outcomes Research Institute, also known as PCORI. I am honored to talk to you today about the importance of telehealth and telemonitoring technologies in supporting family caregivers across the U.S.

I would like to thank Chairman Senator Bill Nelson for drawing attention to this critical issue, the Members of the Committee, and their staff. Thank you.

By way of background, the Alliance is a non-profit coalition of nearly 50 national organizations who have joined together to advance the work of family caregiving. Our primary mission is to conduct public policy research on family caregivers and to spur innovation and advocacy that supports the work of caregiving. In this capacity, we support a network of over 80 state and local caregiving coalitions across the U.S. and serve as Secretariat for an international coalition, the International Alliance of Carer Organizations.

Our previous research has revealed that there are 65.7 million family caregivers in the United States, many of whom are balancing other responsibilities such as caring for children, career, or planning for their own future. This number continues to grow, as reported by the Pew Internet and American Life Project which found in 2013 that 39% of U.S. adults (or four out of ten) are caregivers. Pew describes these caregivers as "wired for health," meaning that they increasingly rely on online tools and information to support their loved ones.

We agree. Our 2011 study on e-Connected Caregivers found that more than 70% of caregivers would find the following technologies very useful in providing care: personal health record tracking (77%), caregiving coordination systems (70%), and a medication support system (70%). Many in-home telehealth devices offer these capabilities, and the ability of the patient or caregiver to enter information from the comfort of the home. Yet over 40% of caregivers reported perceived barriers to trying these new technologies, including the belief that the technology will be expensive.

These fears are not unfounded. The out-of-pocket costs that caregivers must incur to support their loved ones are of continuing concern. This Committee has spoken eloquently in the past about the need to create a long-term care plan for Americans and to bridge the gaps of the Medicare, Medicaid, and Social Security programs which are insufficient to address the needs of an aging population. Private long-term care insurers continue to reduce the number of insurance products available to support the needs of aging, chronically ill individuals. Without support from government or the private insurance market, family caregivers – who are *unpaid* friends and family members – have become the backbone of our society's long-term care system. Technology, and telehealth, can offer a means to ease some of this burden, but only to the extent that these technologies are made affordable and accessible.

At the Alliance, we have fostered discussions with the designers of caregiving technologies to address issues with access and usability. In March, we co-convened a roundtable of Silicon Valley entrepreneurs, government officials, non-profit organizations, and thought-leaders to discuss how technologies can be better designed to meet the needs

of the caregiver. As a result of this round table, the Alliance was pleased to release a new report with recommendations for moving innovation forward. The *Catalyzing Technology to Support Family Caregiving* report offers six suggestions for improving caregiving technologies. This report and our other work in technology can be found on our website at wwww.caregiving.org/research/technology.

I would like to share the recommendations from the report briefly with you now:

1. Create better "concept maps" and find more appropriate language to describe the varied and complex caregiving landscape.

2. Continue to collect extensive data about the prevalence, burden, and impact of caregiving and the role of technology.

3. Spur a broad national conversation on caregiving.

4. Develop compelling business cases for employers and healthcare providers to support caregiving.

5. Provide caregiving coaching as an integral component of all solutions.

6. Inspire social conversations about caregiving to encourage more learning and support within families and communities.

We are encouraged by this Committee's attention to the issues that family caregivers face as our society continues to age. We believe that technology is part of the solution to the long-term care crisis and look forward to continuing innovation that will provide better support to the families who are managing the illnesses and disabilities of their loved ones.

Thank you again for your time.