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CAN LAUNCHES WEBSITE FOR RARE DISEASE CAREGIVERS

Today, the Caregiver Action Network (CAN) announced the launch of 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.

An estimated 350 million people worldwide suffer from rare diseases – including 30 million in the United States and another 30 million in Europe. Launch of www.RareCaregivers.org coincides with the 7th Annual World Rare Disease Day on Friday, February 28, 2014. World Rare Disease Day 2014, whose theme is “Join Together for Better Care,” raises awareness for rare diseases and improving access to treatments and medical representation for individuals with rare and genetic diseases and their families.

The website at www.RareCaregivers.org is a guide for family caregivers of loved ones with rare diseases and features information helpful to the caregiver (known around the world as carer, cuidador, soignant, betreuer, and other phrases, depending on the country) such as:

- ✓ Caregiving Information You Can Use Now
- ✓ Take Care of Yourself
- ✓ Complex Emotions
- ✓ Family Matters
- ✓ Other Places to Turn for Help

CAN’s new “Caring for Rare Disease Caregivers” website was supported with funding from Genzyme, a leading biotechnology company whose mission is to develop and deliver transformative therapies for patients with unmet medical needs.

“This new website will be an exceptional resource to help families in their rare disease caregiving journey,” said Toni Mathieson, Executive Director, Niemann-Pick Disease Group (UK) and Board Member of the International Niemann-Pick Disease Alliance. “There are millions of rare disease caregivers around the world who need caregiving information and support networks,” she added.

Caregiver Action Network created the new “Caring for Rare Disease Caregivers” website to address the needs expressed by actual rare disease caregivers. In a meeting with CAN in 2013, rare disease caregivers reported unmet needs related to social support, self-care and connections across diagnoses; and expressed a clear consensus opinion that they would be well served by a resource they could access dedicated to their needs as a caregiver, in addition to the disease specific resources they already utilized. CAN then worked with a special, international task force of rare disease caregivers in developing the new “Caring for Rare Disease Caregivers” website.

The Caregiver Action Network invites rare disease patient organizations around the world to link to the new www.RareCaregivers.org website. As John Schall, CEO of CAN, explained, “The new website is focused only on *caregivers*, not on *patients*. Disease-specific organizations are the real experts for information on a host of rare diseases like Pompe’s, Tay-Sachs, Huntington Disease or Gaucher’s, for example. We welcome partnerships with rare disease organizations and patient groups so that we can help them by providing resources solely directed towards the caregiver of a loved one with a rare disease.”

About CAN

The Caregiver Action Network (www.CaregiverAction.org) is the nation’s leading family caregiver organization working to improve the quality of life for the than 90 million Americans who care for loved ones with chronic conditions, disabilities, disease, or the frailties of old age. CAN serves a broad spectrum of family caregivers ranging from the parents of children with special needs, to the families and friends of wounded soldiers; from a young couple dealing with a diagnosis of MS, to adult children caring for parents with Alzheimer’s disease. CAN (formerly the National Family Caregivers Association) is a 501(c)3 non-profit organization providing education, peer support, and resources to family caregivers across the country free of charge.

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