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Leading Patient Organizations Establish Partnership to Improve the Lives of Tens of Millions of Rare Disease Patients in Japan and the U.S.

Japan Patients Association (JPA) and National Organization for Rare Disorders (NORD) to Collaborate Toward New Treatments and Improved Policies

January xx, 2013, WASHINGTON-----The Japan Patients Association (JPA) and the National Organization for Rare Disorders (NORD)—the primary organizations representing patients and families affected by rare diseases in Japan and the U.S.—announced today that they have signed a memorandum of understanding to collaborate and improve the lives of their constituents.

The partnership uniting the JPA and NORD was formally established in Washington, D.C., on January 8, 2013, by Tateo Ito, president of the JPA, and Peter L. Saltonstall, president and CEO of NORD.

“Our organizations have a shared mission and goals” Ito said. “We would like to make use of our valuable knowledge and experiences for the mutual benefit of patients in both countries.”

“Global collaboration will drive progress toward new treatments, improved public policies and better lives for people with rare diseases,” Saltonstall said. “We look forward to working together on behalf of the rare disease communities in Japan and the U.S., reinforcing our commitment to partnerships that advance patients’ needs.”

Per the memorandum of understanding, “it is becoming increasingly evident that addressing challenges related to rare and intractable diseases often requires international collaboration ... patients, their families and patient organizations affected by rare and intractable diseases often share similar challenges even though they may live in different parts of the world.”

A declaration of shared commitment to improving the lives of rare disease patients and families, the partnership specifies that the two organizations will share information about current advocacy initiatives and seek ways to increase understanding and communication between rare disease patients and patient organizations in Japan and the U.S.

About the Japan Patients Association

The JPA is a non-profit umbrella organization established in 2005. It focuses on rare and intractable diseases and has a membership of approximately 300,000 from 72 organizations, including individual patient groups and regional centers. JPA provides patient/family services and advocacy on public policies. It also collaborates with other organizations in Japan and organizes patients' forums.

For more information, please visit (insert website).

About NORD

Celebrating its 30th anniversary year, the National Organization for Rare Disorders (NORD) is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. A nonprofit organization, NORD represents the 30 million Americans with rare diseases and is committed to the identification, treatment and cure of rare disorders through patient assistance, education, advocacy and research. NORD represents approximately 200 member organizations.

In addition to this new partnership with JPA, NORD also has a strategic alliance with EURORDIS (Rare Diseases Europe) to connect rare disease patients in the U.S. and Europe through global online communities (www.RareConnect.org) and other initiatives.

For more information, please visit www.rarediseases.org.