MEMORANDUM OF UNDERSTANDING

Japan Patients Association (JPA)

and the

National Organization for Rare Disorders (NORD)

January 8, 2013
JAPAN PATIENTS ASSOCIATION (JPA) AND
THE NATIONAL ORGANIZATION FOR RARE
DISORDERS (NORD)
MEMORANDUM OF UNDERSTANDING

WHEREAS, the Japan Patients Association (JPA) and the National Organization for Rare Disorders (NORD) have come together to collaborate to improve the lives of patients affected by rare and intractable diseases and living in Japan or the USA; and

WHEREAS, the partners listed below have agreed to enter into a collaborative agreement to work together in areas identified as of mutual interest; and

WHEREAS, it is becoming increasingly evident that addressing challenges related to rare and intractable diseases often requires international collaboration; and

WHEREAS, 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;

THEREFORE, the Japan Patients Association (JPA) and the National Organization for Rare Disorders (NORD) do issue this declaration of shared commitment to improving the lives of the patients and families they represent and declare their intention of identifying areas in which to collaborate on initiatives related to advocacy, education, awareness and other topics of importance to the rare and intractable disease community.
Description of Partner Agencies

The Japan Patients Association (JPA) is a non-profit organization established in 2005. JPA is an umbrella association related to “NANBYO”, rare and intractable diseases. Total membership of JPA is about 300,000 from 72 organizations including individual patient groups and regional centers (as of 2012). The mission of JPA is “Construct a people-oriented medical treatment and welfare social system” and “Try to establish Japan’s National Center”. JPA provides patient/family services, lobbying to the government, petition to the congress, and so on. JPA also collaborates among other associations in Japan and has organized patients’ forums since 2012.

The National Organization for Rare Disorders (NORD) is a non-profit, 501©3 organization established in 1983. It serves as the primary advocacy organization for the 30 million Americans with rare diseases and those seeking to improve their lives. NORD provides programs of advocacy, education, research and patient/family services through its offices in Washington DC; Danbury, CT; and Quincy, MA. It also provides mentoring for rare disease patient organizations and particularly for its 200 member organizations, and seeks to enhance physician and public awareness of rare diseases and of the challenges of living with a rare disease.

Roles and Responsibilities

Initially, the collaboration between JPA and NORD will focus on general activities designed to increase understanding and communication between rare disease patients and patient organizations in Japan and the USA. Such activities will include:

- Sharing information about rare disease patient

双方の患者協議会について

JPA は、2005年に設立された希少・難治性疾患領域患者協議会であり、2011年からは一般社団法人として活動しています。加盟組織は、個別患者会ならびに地域難病連であり、2012年12月現在で72組織、約30万人が活動しています。当該領域における豊かな医療と福祉の実現を目指しており、National level の患者協議会として、情報発信、政策提言、政府委員会参加等を積極的に実施しています。近年では、他の患者会を束ねたフォーラム開催等も行っており、患者意見の共有・統一を目指しています。

NORD は1983年に設立した非営利機関です。NORD は、希少疾患患者および彼らの生活改善に向けた支援をしている国内約3000万人に対する主要な支援組織です。NORD は支援、教育、研究および患者/患者家族へのサービスもしくはプログラムを実施しております。オフィスはワシントン DC、ダンバリー（コネチカット）、クインシー（マサチューセッツ）の3か所にあります。さらに、NORD は会員である200の患者会および患者支援組織に対し、認知度向上や研究者支援を目指す患者会への相談事業を実施していまます。

責任および役割

はじめに、JPA と NORD 間の連携は、日本およびアメリカ合衆国における希少疾患患者と患者会の間のコミュニケーションならびに相互理解を深めることを目的とした全般的活動に焦点をあてます。すなわち、日本およびアメリカ合衆国における希少疾患患者会に関
organizations in Japan and the USA
- Sharing information about current advocacy initiatives in Japan and the USA
- Displaying the logo of the partner organization, with a statement of collaboration and friendship, on each organization’s website
- Issuing a joint press release about the collaboration between the two organizations

Commitment to Partnership

We, the undersigned, have read and agree with this MOU. We approve this declaration of friendship and collaboration, and declare our intent to investigate other, more formal ways of working together in the future.

Peter L. Saltonstall  ピーター・サルトンストーリー
President and CEO, NORD
NORD 代表兼 CEO

2013 年 1 月 8 日
January 8, 2013

伊藤たてお  Tateo Itoh
President, JPA
JPA 代表理事

伊藤建雄