

News release

Kyowa Kirin Joins the Newly Established STEP Information Community for Rare Disease Stakeholders in Japan

Tokyo, Japan, December 24, 2021 --Kyowa Kirin Co., Ltd. (TSE:4151, President and CEO: Masashi Miyamoto, "Kyowa Kirin") announces that it has joined the newly established information community for rare disease stakeholders named STEP (Strategic Translational Action for Empowering Patient, STEP Community) by ASrid, a non-profit organization in Japan that aims to connect patients, their families, and various related parties in the field of rare and incurable diseases as an "intermediary organization"

STEP is an abbreviation for "Strategic Translational Action for Empowering Patients". The STEP Community aims to "provide a strategic bridge for patients and their families to demonstrate their power." Specifically, by disseminating information through the STEP website and holding lectures according to their needs, the STEP Community will contribute to empowering patients, their families, and other concerned parties (building their power and confidence) with the collaboration with healthcare professional from 1) a disease area perspective and 2) a cross-sectional perspective.



"It's undeniable that the current insufficient information on rare and intractable diseases and the limited ways to obtain such information in Japan is a social problem, in the meanwhile, we feel that there are limits to what a single company could do to provide the wide range of information needed by patients with rare and intractable diseases, and their caregivers," said **Takeyoshi Yamashita, Ph.D., Managing Executive Officer, Director of Corporate Strategy & Planning Department in Kyowa Kirin**, "We totally agreed with the purpose and welcome the establishing STEP, an information community for rare diseases and decided to participate in it. Kyowa Kirin will work closely with the community to contribute to the creation of an environment that responds to the "need to know" of patients and other stakeholders involved in rare and intractable diseases."

"We are very encouraged by the participation of Kyowa Kirin, which has strengths in antibody drugs and antibody technology and has set "address patient-centric healthcare needs" as one of the company's strategies," commented **Yukiko Nishimura, Board member of ASrid**, "we truly believe that apart from healthcare professionals, the contribution from companies is essential to the challenge of disseminating appropriate information to patients, their families, and other stakeholders

through the STEP community. By promoting STEP activities with the cooperation of Kyowa Kirin and other companies as well as various stakeholders, we hope that STEP will become a "correct index" and "selectable index" of information necessary for all people involved in the relevant diseases, and that the information that stakeholders "want" to deliver will help match the information that patients, their families, and others want."

At STEP community, 2 initiatives will be launched first, 1) "STEP Bone disease" targeting rare and incurable bone system diseases and metabolic bone diseases 2) "STEP Learning" as a gateway for learning "knowledge" and "information" in the field of rare and incurable diseases. Kyowa Kirin will join both initiatives and make contribution with our experience in running disease information website related to FGF23-related hypophosphatemic rickets and osteomalacia, a rare bone disease.

The Kyowa Kirin Group companies strive to contribute to the health and well-being of people around the world by creating new value through the pursuit of advances in life sciences and technologies.

About STEP Community

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For more information, please visit ASrid website: <https://asrid.org/en>

About ASrid

ASrid is a non-profit organization that aims to connect patients, their families, and various related parties in the field of rare and incurable diseases as an "intermediary organization". Under the slogan of "To Patients, For Patients, Beside Patients", ASrid conducts a wide range of activities, from conducting research and providing support for specific diseases to promoting international collaboration across diseases and holding social awareness events. ASrid also collaborates with patients, their families, patient groups and councils, as well as medical professionals, researchers, companies, and governments in this field.

ASrid website: <https://asrid.org/en/>

Kyowa Kirin and Patient Advocacy in Japan

As Kyowa Kirin set in its 2021-2025 Medium-Term Business Plan, "address patient-centric healthcare needs" is one of the company's important strategies. In April 2021, a new function focus on patient advocacy was newly set up to lead the activities for patients and their caregivers in Japan. Through

communication and cooperation with patients and healthcare professional communities in our core therapeutic areas (nephrology, oncology, immunology/allergy, and central nervous system), including Rare Disease Day in Japan, which we have been participating in since 2019, the function aims to promote sound public understanding of medical conditions and create life-changing value that make people smile.