NPO ASrid

> ## Annoucement of Launch of the "STEP LEARNING" Website
> ## Information Portal Website Responding to the "Want to Know" of
> ## People with Rare and Intractable Diseases

ASrid, a non-profit organization (located in Bunkyo-ku, Tokyo; President: Yukiko Nishimura), announces the launch of the "STEP LEARNING" website, an information portal website that responces to the "want to know" for patients, families, and other stakeholders in the field of rare and intractable diseases.

There are many stakeholders in the field of rare and intractable diseases, and each stakeholder is involved in a variety of activities. We believe that the dissemination of a wide variety of information from stakeholders in different positions is beneficial to all stakeholders involved, not to mention patients and their families.

On the other hand, it is not easy for these stakeholders to properly receive the information sent by others. Differences exist depending on the diseases, the existence of patient groups, the level of interest of researchers, and the status of drug development.

Under these circumstances, ASrid established "STEP", Strategic Translational Action for Empowering Patients, in December 2021, together with companies and healthcare professionals, for the purpose of "disseminating correct information obtained from appropriate stakeholders from various angles and responding to the 'want to know' of all people concerned, including patients and families".

STEP was initially launched to target disease areas, but after many discussions with stakeholders, we realized the importance of consolidating the knowledge that people involved in the disease area would like to obtain. We also realized that it is necessary to consolidate information that responds to the "wants to know" of those involved in the STEP, not only by disease area, but also by purpose.
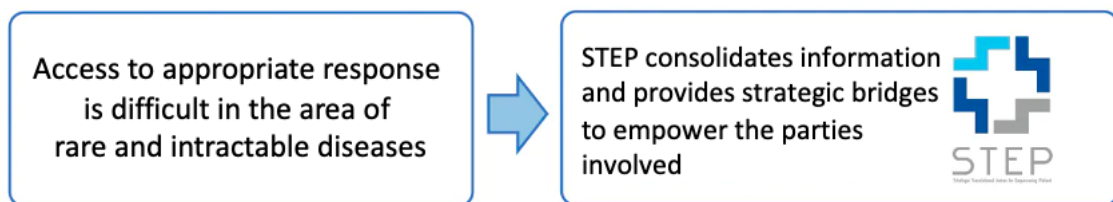
Based on these ideas, we are pleased to announce the release of "STEP LEARNING", an information portal website that organizes "want to know" by purpose, which will be helpful to those involved in the relevant fields.

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STEP LEARNING Website: https://www.step-rd.info/

【What is "STEP"?】
　　STEP stands for "Strategic Translational Action for Empowering Patients". STEP aims to implement strategic bridges to empower patients and their families.

　　Specifically, by disseminating information through the STEP website and holding lectures and other events according to the needs of patients and their families, STEP will contribute to empowering patients and their families from two perspectives (groups): 1) the disease area perspective and 2) the cross-disciplinary perspective for each purpose. The first perspective will be designed longitudinally by disease area, not by individual disease, and will be expanded in the future; the second perspective will be designed by purpose across diseases, adding the knowledge and information necessary for each area. In order to clarify the position of the project as a non-profit project, both will be launched when more than three companies are expected to participate.

【What is "STEP LEARNING"?】
　　"STEP LEARNING" was established to respond to the needs of patients, families, and other stakeholders in the field of rare and intractable diseases from various perspectives on 7 topics related to all rare and intractable disease areas.

➢ **Rare Disease in General**: Introducing general RD (Rare Disease) topics and organizations
➢ **Genome(Genes)**: Introducing contents for learning basic and applied knowledge of the genome and genes
➢ **Clinical Trials**: Introducing content to better understand clinical trials, as well as a search website for clinical trials, status and results

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- ➢ **Medicines:** Information on how to use drugs, useful search websites for individual drugs, and science and technology used in pharmaceutical research
- ➢ **Law/Policy:** Introducing contents for learning about drug development in the field of rare and intractable diseases, as well as laws and policies surrounding the medical care and lives of patients
- ➢ **Social Welfare:** Introducing contents on social welfare services that may be available to patients and their families.
- ➢ **Patient and Public Involvement (PPI):** Introducing contents related to PPI to make the voices of patients and their families heard.

The content to be posted on each topic will be collected from all stakeholders, including patients and their families, patient groups, medical professionals, companies, and government, and will be disseminated after careful examination of the content in collaboration with the supervisors, to serve as an entrance to useful information. We are also considering adding new content, producing new content, and holding lectures in response to requests from stakeholders participating in STEP as a community.
Companies participating in the "STEP LARNING" project include not only pharmaceutical companies, but also medical device manufacturers, CROs, medical IT companies, and companies in related industries. In particular, as the industry involved in this field, we have opened our doors to a wide range of stakeholders, including not only pharmaceutical companies but also companies in the information sector.

It is our hope that the promotion of STEP activities will serve as a "Correct index" and "Selectable index" of necessary information for all people involved in the disease, and will help match the information that patients, families, and other people "Want to Know" with the information that stakeholders "Want to Deliver".

【STEP Community Participating Companies】 （as of May 2022）

Company Name (in alphabetical order)	Company Attributes
Alnylam Japan K.K. https://www.alnylam.jp/	Pharmaceutical company
Daiichi Sankyo Company, Limited	Pharmaceutical company

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https://www.daiichisankyo.com/	
Illumina K. K. https://www.illumina.com/	Medical device manufacturer
Kyowa Kirin Company, Limited https://www.kyowakirin.com/	Pharmaceutical company
Novartis Pharma K.K. https://www.novartis.com/	Pharmaceutical company
Parexel https://www.parexel.com/	CRO (Contract Research Organization)
PeptiDream Inc. https://www.peptidream.com/	Pharmaceutical company
Takeda Pharmaceutical Company Limited https://www.takeda.com/	Pharmaceutical company
Xcoo, Inc. https://xcoo.jp/	Medical IT company

【Supervisor】
STEP LEARNING is supervised by **Amane Koizumi, MD, Ph.D**. After graduating from Keio University School of Medicine, Dr. Koizumi worked in the Department of Physiology at Keio University School of Medicine and at Harvard Medical School and Massachusetts General Hospital, where he conducted research in electrophysiology and retinal visual neuroscience. In 2013, he moved to the National Institutes of Natural Sciences (NINS) Headquarters, where he is currently serving as a specially-appointed professor and supervising URA in the Office for Enhancing Research Capability. In the STEP LEARNING project, Dr. Koizumi is in charge of supervising the contents based on his rich experience and knowledge of science communication and public relations outreach activities.

【STEP Secretariat（Located inside ASrid, a non-profit organization）】
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

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collaborates with patients, their families, patient groups and councils, as well as medical professionals, researchers, companies, and governments in this field.

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