

## Joint Statement on Improvement of Drug Lag/Loss and Patient Access to Clinical Trial Information

European Federation of Pharmaceutical Industries and Associations  
(EFPIA Japan)



On October 9, 2024, the European Federation of Pharmaceutical Industries and Associations (EFPIA Japan) convened at the Patient Forum 2024 in Tokyo, bringing together stakeholders from various backgrounds to engage in transparent discussions on current situations and future challenges regarding drug lag and loss and patient access to clinical trial information. The forum aimed to promote patient-inclusive drug development and contribute to public health and the advancement of Japanese healthcare through collaboration.

As a result of discussions at the forum, the panel concluded that addressing drug lag/loss issues and improving patient access to clinical trial information and subsequent treatments are essential to protect lives from diseases, including rare cancers and intractable diseases, support the development of medical technologies and research, and ensure the soundness and sustainability of the social insurance system. To this end, we hereby issue this joint statement to inform the Japanese public of our shared concerns widely.

At Patient Forum 2024, we confirmed the following two points that contribute to the current situation and challenges faced in healthcare in Japan:

Firstly, Japan's social security system, established in 1961, is a world-class system that guarantees all citizens access to necessary medical services through public health insurance. Based on the concepts of self-help, public assistance, and mutual aid, with mutual aid at its core, this system provides a foundation for society to support healthcare. The drug lag/loss issue<sup>1</sup> that emerged in the late 2010s primarily affected unapproved drugs originating from overseas venture companies without a domestic base in Japan. The 2024 drug pricing system reform introduced measures to reward innovative new medicines and promote their rapid introduction in the country. Additionally, recent regulatory reforms encourage overseas ventures to develop medicines in Japan. These reforms are expected to be the first step in resolving the drug lag/loss issues and promoting new drug development by foreign-affiliated companies in Japan. Continued reforms reflecting an attractive Japanese market will likely generate further investment and employment from multi-national pharmaceutical companies.

However, current challenges include the lack of prioritization discussions to allocate limited healthcare resources effectively to swiftly deliver essential medicines and life-saving innovations for intractable diseases to patients. Opportunities are limited to discuss and exchange among multi-stakeholder discussions, including patient groups and support organizations, to find optimal solutions for the drug lag/loss issues. Furthermore, while 86 drugs<sup>2</sup> were reportedly undeveloped in Japan as of the end of 2022, the details have not been publicly scrutinized. There is a need for stakeholders to work together to prioritize the approval of life-saving drugs and those for intractable diseases. Additionally, the availability of therapeutics and indications does not always align with the need of patient groups and individual patients, necessitating that relevant stakeholders pay more attention to patients' voices. Recently, notable trials of innovative medicines in Asia have shifted to China and Korea, with some cases where trials are not even conducted in Japan due to complex regulatory systems, exacerbating the situation where drug availability is uncertain. These challenges require action from each stakeholder's position.

Secondly, in Japan, the Handling of Clinical Trials Information Provision<sup>3</sup> outlines requirements for pharmaceutical companies to provide clinical trial information, allowing the information provision of trial drug names and trial codes. For patients with rare cancers and intractable diseases who have limited treatment options, clinical trials can be an effective choice. Our forum brought to light cases in which patients who had exhausted standard treatment options participated in clinical trials, emphasizing the importance of providing information to help patients avoid missing opportunities to

consider trial participation. Naturally, participation in clinical trials carries the risk of unknown side effects and does not guarantee efficacy. Clinical trial enrollment requires medical judgment by trial physicians, and eligibility criteria are strictly managed.

However, clinical trial sites are limited, and the media that provides trial information is restricted to healthcare professionals, leading to concerns that healthcare providers are not adequately sharing trial information. Clinical trial information disseminated by pharmaceutical companies is strictly limited to those seeking information about clinical trials and is not widely accessible to the public. Yet in France, for example, the government promotes the clear disclosure of clinical trial information to the public, and in the United States, clinical trial information is often provided by specialists along with standard treatment options after diagnosis, offering opportunities to understand the concept of clinical trials correctly. In Japan, few people receive explanations from specialists, resulting in limited opportunities to understand correctly and address misconceptions and biases about clinical trials. Furthermore, when pharmaceutical companies provide clinical trial information to the general public beyond those seeking information about clinical trials, it falls under the Applicability of Pharmaceutical Advertising in the Pharmaceutical Affairs Law<sup>4</sup>, which prohibits the provision of information including trial drug names and codes.

Based on the current situation and discussions for problem-solving through industry-government-academia-patient collaboration at Patient Forum 2024, we agreed that the following actions are required as we move forward:

**Prioritization Based on Limited Healthcare Resources:** Continuously discuss the maintenance of universal health insurance coverage, recognizing it is critical to prioritize the swift delivery of essential medicines and life-saving innovations to patients and continuous discussions are needed.

**Promoting Innovation:** To expedite the delivery of innovations to patients, it is essential to examine the drug lag/loss issues, continuously review pharmaceutical regulations and drug pricing systems, and work together with stakeholders to position the pharmaceutical industry as a key industry in Japan.

**Access to Clinical Trial Information:** Making clinical trial information more accessible to patients requires reforms and system improvements, including deregulation. In particular, patient access to clinical trial information which is reported to the Pharmaceuticals and Medical Devices Agency (PMDA) by companies and organizations should be facilitated.

To resolve these issues, the statement participants commit to active opinion sharing, engaged discussion, and taking action to develop more suitable policies and systems, including approaching

government stakeholders for action to improve public health and advance Japanese healthcare.

Sources:

\*1. Definition of Drug Lag/Loss: Drug lag refers to the issue in which drugs already approved overseas take many years to be approved in Japan. Drug loss refers to the situation in which therapeutic drugs already in use in Western countries and other foreign markets are not being developed in Japan, meaning pharmaceutical companies have no plans to develop them, and thus they are unavailable for use in Japan.

\*2. Reference material from the Expert Committee Report on Comprehensive Measures for Realizing Rapid and Stable Supply of Pharmaceuticals, June 9, 2023.

\*3. PFSB/ELD Notification No. 0124-1, dated January 24, 2023.

\*4. PMSB/ELD Notification No. 148, dated September 29, 1998.

[Statement Participants]

Yoshiyuki Majima  
Director, Rare Cancers Japan

Ichiro Innami  
Professor Emeritus, Keio University  
Deputy Director General, Institute for Health Economics and Policy

Shinsuke Amano  
President, Japan Federation of Cancer Patient Groups

Tsuji Kunio  
Executive Director, Japan Patient Association

Takahiko Iwaya  
Chairman EFPIA Japan

[Organizations Participating in the Joint Statement]

**About the Rare Cancers Japan (<https://rarecancersjapan.org/>)**

The Rare Cancer Japan was established in August 2017 aiming to build a society in which rare cancer patients and families can live with confidence and dignity by working on improving the situation of rare cancers because the number of patients with rare cancers has been small, which has delayed the development of treatment systems, the development of treatments, basic research, and the disclosure of information. Our vision is to create a world where no one dies from rare cancers and continue our efforts to improve the rare cancer medical care system, including the development of specialized facilities and consultation centers, including specialist education, and the development of treatments and new drugs.

**About the Institute for Health Economics and Policy (IHEP) (<https://www.ihep.jp/>)**

The Institute for Health Economics and Policy (IHEP) is a research institution established in 1993 with the approval of the Minister of Health and Welfare, aiming to promote research on health economics and healthcare/long-term care policies in Japan. To contribute to the development and improvement of healthcare and long-term care policies, IHEP conducts empirical research on various phenomena using economics and other methodologies. Additionally, IHEP collects and accumulates information on health economics, promotes awareness, and fosters specialized research in this field.

**About the Japan Federation of Cancer Patient Groups (<https://zenganren.jp/>)**

The Japan Federation of Cancer Patient Groups was established in May 2015 as a nationwide federation of cancer patient organizations. Its purpose is to promote cooperation and activities among cancer patient groups, address issues in treatment, care, and daily life for cancer patients and their families, and contribute to improving cancer care and building a society where people can live with peace of mind even after a cancer diagnosis. The federation engages in various new activities in collaboration with different stakeholders to realize "the improvement of cancer care and the creation of a society where people can live with peace of mind even after a cancer diagnosis."

**About the Japan Patients Association (JPA) (<https://nanbyo.jp/>)**

The Japan Patients Association (JPA) is a national organization comprising rare and chronic disease patient groups as full and associate members. JPA aims to resolve the challenges faced by patients with rare diseases and their families through social means, gaining understanding from citizens and the public, and realizing a society where patients and their families are respected as human beings. In addition to advocating for legislation and administrative changes through parliamentary petitions, raising public awareness about rare diseases, and facilitating patient and family exchanges, JPA also conducts patient support activities, training, and promotes international cooperation as part of a project subsidized by the Ministry of Health, Labour and Welfare.

**About EFPIA Japan (European Federation of Pharmaceutical Industries and Associations Japan)**  
**(<http://efpia.jp/>)**

EFPIA Japan, established in April 2002, comprises 23 European research-based pharmaceutical companies operating in Japan. In 2023, the total sales of member companies accounted for approximately 28% of the Japanese pharmaceutical market. The mission of EFPIA Japan is to contribute to Japanese healthcare and patient health through the early introduction of innovative medicines and vaccines. EFPIA Japan aims to strengthen dialogue with policymakers to improve healthcare in Japan.

## [Patient Organizations Supporting This Joint Statement]

Note: Some patient organizations belong to multiple federations.

Japan Federation of Cancer Patient Groups (50 organizations in total)	
一般社団法人 C S R プロジェクト Cancer Survivors Recruiting Project	サバイバーナースの会「びあナース」 Survivor Nurse Association "Peer Nurses"
特定非営利活動法人 GISTERS Not-for-Profit Organization GISTERS	小児脳腫瘍の会 Pediatric Brain Tumor Society
特定非営利活動法人 腺友倶楽部 NPO Gland Club	吹田ホスピス市民塾 Suita Citizens Hospice
特定非営利活動法人 H O P E プロジェクト NPO HOPE Project	精巣腫瘍患者友の会 J-TAG J-TAG Testicular Cancer Patients Association
一般社団法人 Team CML @Japan NPO, Team CML Japan	特定非営利活動法人 市民と共に創るホスピスケアの会 NPO Hospice Care Association Created by Citizens
特定非営利活動法人 あいおぶらす NPO AIOPLUS	はーべすと（奈良の患者サポートと地域・医療連携を考える会） Harvest (Association for Patient Support and Regional/Medical Cooperation in Nara)
特定非営利活動法人 いきいき和歌山がんサポート NPO Ikiiki Wakayama Cancer Support	特定非営利活動法人 中皮腫サポートキャラバン隊 NPO Mesothelioma Support Caravan
特定非営利活動法人 愛媛がんサポートおれんじの会 Ehime Cancer Support, Orange Association (NPO)	徳島県がん患者団体協議会 Tokushima Cancer Patients Association
一般社団法人 神奈川県がん患者団体連合会 Kanagawa Prefecture Cancer Patients Association	奈良がんピアサポートなぎの会 Nagi Association for Nara Cancer Peer Support
がん患者会ネットワークかがわ Kagawa Cancer Patients' Association Network	奈良県のホスピスとがん医療をすすめる会 Association to Promote Hospice and Cancer Care in Nara Prefecture
患者会「コスモス」 Cosmos Cancer Patient Association	認定特定非営利活動法人 乳がん患者友の会きらら NPO Kirara Breast Cancer Patient Friendship Association
一般社団法人がんチャレンジャー NPO Cancer Challengers	ねむの樹 (Social welfare corporation) Nemunoki
特定非営利活動法人 がんと共に生きる会 NPO Living with Cancer Association	特定非営利活動法人 脳腫瘍ネットワーク NPO Brain Tumor Alliance
特定非営利活動法人 がんピアネットふくしま NPO Fukushima Cancer Peer Network	肺がん患者会 ワンステップしゃちほこ Lung Cancer Patients' Association One Step Shachihoko
特定非営利活動法人 がんフォーラム山梨 NPO Yamanashi Cancer Forum	特定非営利活動法人 肺がん患者の会ワンステップ NPO One Step Lung Cancer Patients' Group
認定特定非営利活動法人 希望の会 NPO "Kibonokai" Hope Association	肺がん HER2 「HER HER」 Lung Cancer HER2 (HER HER)

特定非営利活動法人 キャンサーサポート NPO Cancer Support	特定非営利活動法人 パンキャンジャパン NPO Pancreatic Cancer Action Network
特定非営利活動法人 キュアサルコーマ NPO Cure Sarcoma	ひょうごがん患者連絡会 Hyogo Cancer Patients Association
京都乳がんピアサポートサロン～fellows～ Fellows Salan, Kyoto Cancer Peer Support	特定非営利活動法人 ブーゲンビリア NPO Bougainvillea
京都府がん患者団体等連絡協議会 Kyoto Prefecture Cancer Patient Organization Council	北海道肺がん患者と家族の会 Hokkaido Lung Cancer Patients and Families Association
特定非営利活動法人 京都ワーキング・サバイバー NPO Kyoto Working Survivors	特定非営利活動法人 ミーネット NPO ME Net
一般社団法人 グループ・ネクサス・ジャパン Group Nexus Japan	ゆうかぎの会（離島におけるがん患者支援を考える会） Yuukagi no Kai (Association for Supporting Cancer Patients in Remote Islands)
一般社団法人 高知がん患者支援推進協議会 Kochi Cancer Patient Support	リンチ症候群患者家族会 ひまわりの会 Sunflower Association (Lynch Syndrome Patients' Advocacy Group)
相模原協同病院 がん患者会 富貴草 Sagamihara Kyodo Hospital Cancer Patients Association Fukiso	リンパ浮腫ネットワークジャパン Lymphedema Network Japan
特定非営利活動法人 支えあう会「α」 NPO Cancer Support Group "a"	和歌山県がん患者連絡協議会 Wakayama Cancer Patients Council

<b>Japan Rare Cancer Patient Network (20 organizations in total)</b>	
● <b>Pediatric and AYA (Adolescent and Young Adult) Cancer</b>	
小児脳腫瘍の会 Pediatric Brain Tumor Association	「小児脳幹部グリオーマ」シンポジウム開催実行委員会 Executive Committee for the Pediatric Brain Stem Gliomas Symposium
「すくすく」網膜芽細胞腫の家族の会 Sukusuku Retinoblastoma Family Association	横紋筋肉腫 家族の会 Rhabdomyosarcoma Family Network
ユーイング肉腫家族の会 Ewing Sarcoma Family Association	神経芽腫の会 Neuroblastoma Association
一般社団法人 トルコキキョウの会 Eustoma Association	小児脳幹部グリオーマの会 Pediatric Brainstem Glioma Association
<b>Blood Cancers and Other Cancers</b>	
特定非営利活動法人 パンキャンジャパン（神経内分泌腫瘍患者会） NPO Pancreatic Cancer Action Network Japan (Neuroendocrine Tumor Patients Association)	腹膜偽粘液腫患者支援の会 Pseudomyxoma Peritonei Patients' Network of Japan
特定非営利活動法人 キュアサルコーマ	メラノーマ患者会 Over The Rainbow



NPO Cure Sarcoma	Melanoma Patient Group Over The Rainbow
特定非営利活動法人 GISTERS NPO GISTERS	中皮腫・アスベスト疾患・患者と家族の会 Mesothelioma, Asbestos Disease, Patient and Family Association
肉腫（サルコーマ）の会 たんぽぽ Sarcoma Association Dandelion	特定非営利活動法人中皮腫サポートキャラバン隊 NPO Mesothelioma Support Caravan
特定非営利活動法人脳腫瘍ネットワーク Brain Tumor Network	頭頸部がん患者と家族の会 Nicotto（ニコット） Nicotto Head and Neck Cancer Patients and their Families
胸腺腫・胸腺がん患者会 ふたつば Futatsuba Thymoma/Thyroid Cancer Patients Association	シェスタ会 Shesta Association

<b>Japan Patients Association (102 organizations in total)</b>	
<b>Regional Rare Disease Associations</b>	
一般財団法人 北海道難病連 Hokkaido Federation of Intractable Diseases	特定非営利活動法人 愛知県難病団体連合会 NPO Aichi Federation of Intractable Diseases
一般社団法人 青森県難病団体等連絡協議会 Aomori Prefecture Council of Intractable Disease Organizations	特定非営利活動法人 三重難病連 NPO Mie Federation of Intractable Diseases
一般社団法人 岩手県難病・疾病団体連絡協議会 Iwate Prefecture Council of Intractable Disease and Disease Organizations	特定非営利活動法人 滋賀県難病連絡協議会 NPO Shiga Prefecture Council for Intractable Diseases
特定非営利活動法人 宮城県患者・家族団体連絡協議会 Miyagi Prefecture Council of Patient and Family Groups	特定非営利活動法人 京都難病連 NPO Kyoto Federation of Intractable Diseases
特定非営利活動法人 秋田県難病団体連絡協議会 Akita Prefecture Council of Intractable Disease Organizations	特定非営利活動法人 大阪難病連 NPO Osaka Federation of Intractable Diseases
山形県難病団体等連絡協議会 Yamagata Prefecture Council of Intractable Disease Organizations	一般社団法人 兵庫県難病団体連絡協議会 Hyogo Council of Intractable Diseases
福島県難病団体連絡協議会 Fukushima Prefecture Council of Intractable Disease Organizations	特定非営利活動法人 奈良難病連 NPO Nara Intractable Disease Federation
茨城県難病団体連絡協議会 Ibaraki Prefecture Council of Intractable Disease Organizations	和歌山県難病団体連絡協議会 Wakayama Prefecture Council of Intractable Disease Organizations
栃木県難病団体連絡協議会 Tochigi Prefecture Council of Intractable Disease Organizations	広島難病団体連絡協議会 Hiroshima Council of Intractable Disease Organizations
群馬県難病団体連絡協議会 Gunma Prefecture Council of Intractable Disease Organizations	とくしま難病支援ネットワーク Tokushima Intractable Disease Support Network

一般社団法人 埼玉県障害難病団体協議会 Saitama Prefecture Council of Intractable Disease Organizations	愛媛県難病等患者団体連絡協議会 Ehime Prefecture Council of Patients with Intractable Diseases
千葉県難病団体連絡協議会 Chiba Prefecture Council of Intractable Disease Organizations	特定非営利活動法人 高知県難病団体連絡協議会 Kochi Prefecture Council of Intractable Disease Organizations
特定非営利活動法人 神奈川県難病団体連絡協議会 Kanagawa Prefecture Council of Intractable Disease Organizations	福岡県難病団体連絡会 Fukuoka Prefecture Council of Intractable Disease Organizations
新潟県患者・家族団体協議会 Niigata Prefecture Council of Patient and Family Groups	認定特定非営利活動法人 佐賀県難病支援ネットワーク Saga Prefecture Intractable Disease Support Network
山梨県難病・疾病団体連絡協議会 Yamanashi Prefecture Council of Intractable Diseases	特定非営利活動法人 長崎県難病連絡協議会 NPO Nagasaki Prefecture Council for Intractable Diseases
長野県難病患者連絡協議会 Nagano Prefecture Council of Patients with Intractable Diseases	熊本難病・疾病団体協議会 Kumamoto Council of Intractable Disease and Disease Organizations
特定非営利活動法人 岐阜県難病団体連絡協議会 Gifu Prefecture Council of Intractable Disease Organizations	特定非営利活動法人 大分県難病・疾病団体協議会 NPO Oita Prefecture Council of Intractable Disease and Disease Organizations
特定非営利活動法人 静岡県難病団体連絡協議会 NPO Shizuoka Prefecture Council of Intractable Disease Organizations	宮崎県難病団体連絡協議会 Miyazaki Prefecture Council of Intractable Disease Organizations
<b>Disease-specific Organizations</b>	
特定非営利活動法人 IBD ネットワーク NPO IBD Network	側弯症患者の会（ほねっと） Scoliosis Patients' Association (HONETTO)
下垂体患者の会 Pituitary Patients Association	日本 AS 友の会 Japan Ankylosing Spondylitis Club (JASC)
再発性多発軟骨炎（RP）患者会 Relapsing Polychondritis (RP) Patients Association	一般社団法人 日本 ALS 協会 Japan ALS Association (JALSA)
一般社団法人 全国筋無力症友の会 Japan Myasthenia Gravis Association	特定非営利活動法人 日本間質性膀胱炎患者情報交換センター NPO Japan Interstitial Cystitis Patient Information Exchange Center
一般社団法人 全国膠原病友の会 National Collagen Disease Friendship Association	日本肝臓病患者団体協議会 Japan Hepatitis Council
全国 CIDP サポートグループ National CIDP Support Group	特定非営利活動法人 日本マルファン協会 NPO Japan Marfan Association
一般社団法人 全国心臓病の子どもを守る会 National Association for Protecting Children with Heart Disease	フェニルケトン尿症親の会連絡協議会 Phenylketonuria (PKU) Parents Association Liaison Council
一般社団法人 全国腎臓病協議会	ベーチェット病友の会

National Kidney Disease Council	Behcet's Disease Tomo-no-kai Patients' Circle
特定非営利活動法人 全国脊髄小脳変性症・多系統萎縮症友の会 NPO National Spinocerebellar Degeneration and Multiple System Atrophy Friendship Association	もやもや病の患者と家族の会 Moyamoya Disease Patients and Families Association
全国多発性硬化症視神経脊髄炎友の会 National Friendship Association of Multiple Sclerosis Neuromyelitis Optica	特定非営利活動法人 日本オスラー病患者会 NPO Japan Osler's Disease Patients Association
一般社団法人 全国パーキンソン病友の会 National Parkinson's Disease Friendship Association	CFS（慢性疲労症候群）支援ネットワーク CFS (Chronic Fatigue Syndrome) Support Network
一般社団法人 全国ファブリー病患者と家族の会（ふくろうの会） Japan Fabry Disease Patients and Family Association (JFA)	近畿つぼみの会 Kinki Tsubomi no Kai
<b>Associate Member Organizations</b>	
認定特定非営利活動法人 アンビシャス NPO Ambitious	キャッスルマン病患者会 Castleman's Disease Patients Group
SBMA の会（球脊髄性筋萎縮症） Spherospinal Muscular Atrophy Association	日本網膜色素変性症協会 Japan Retinitis Pigmentosa Society
特定非営利活動法人 おれんじの会（山口県特発性大腿骨骨頭壊死症患者会） Orange no Kai (Yamaguchi Idiopathic Osteonecrosis of the Femoral Head Patients' Association)	P X E J a p a n（弾性線維性仮性黄色腫および網膜色素線条症 当事者の会） PXE Japan (Association of Pseudoxanthoma Elasticum and Striae Retinans Patients)
公益財団法人 がんの子どもを守る会 Children's Cancer Association Japan	スティッフパーソンみんなの会 Association of Stiff Persons Patients
特定非営利活動法人日本血管腫・血管奇形患者支援の会（2024年7月30日法人名称変更。旧名称：特定非営利活動法人血管腫・血管奇形の患者会） NPO Japan Association of Hemangioma and Vascular Deformity Patients Support (Corporate name changed on July 30, 2024. (Former name: NPO Hemangioma & Vascular Malformation Patients' Association)	舘島細胞症患者の会 Islet Cell Disease Patients Association
シルバーラッセル症候群ネットワーク Silver Russell Syndrome Network	ギラン・バレー症候群患者の会 Guillain-Barré Syndrome Patients Association
特定非営利活動法人 全国ポンペ病患者と家族の会 NPO National Association of Pompe Disease Patients and Their Families	全国脊柱靭帯骨化症患者家族連絡協議会 National Council of Families of Patients with Spinal Ligament Ossification
一般社団法人 先天性ミオパチーの会 Congenital Myopathy Association	ジストニア・ジスキネジア患者の環境改善を目指す会 Association for the Improvement of the Lives of Dystonia and Dyskinesia Patients
高安動脈炎友の会（あけぼの会）	サルコイドーシス友の会

Takayasu Arteritis Friendship Association (Akebonokai)	Sarcoidosis Friendship Association
竹の子の会 (プラダー・ウィリー症候群児・者親の会) Takenoko no Kai (Association of Parents of Children and Persons with Prader-Willi Syndrome)	特定非営利活動法人 境を越えて NPO Beyond Boundaries
つくしの会 (全国軟骨無形成症患者・家族の会) Tsukushi no Kai (National Association of Chondrodysplasia Patients and Their Families)	みやぎ化学物質過敏症の会～ぴゅあい～ Miyagi Chemical Substance Hypersensitivity Association ~PYUAY
特定非営利活動法人 難病支援ネットジャパン NPO Intractable Disease Support Network Japan	一般社団法人 ピーベック PPeCC
特定非営利活動法人 新潟難病ネットワーク NPO Niigata Network for Intractable Diseases	特定非営利活動法人 両育わーど NPO Ryoyuiku World
認定特定非営利活動法人 日本 IDDM ネットワーク Certified NPO Japan IDDM Network	特定非営利活動法人 線維筋痛症友の会 NPO Fibromyalgia Friendship Association
日本ゴーシェ病の会 Association of Gaucher Disease Patients in Japan	SMA (脊髄性筋萎縮症) 家族の会 SMA (Spinal Muscular Atrophy) Family Association
特定非営利活動法人 日本プラダー・ウィリー症候群協会 NPO Prader-Willi Syndrome Association Japan (PWSA Japan)	MECP2 重複症候群患者家族会 MECP2 Duplication Syndrome Patient Family Association
特定非営利活動法人 PADM 遠位型ミオパチー患者会 NPO PADM (Patients Association for Distal Myopathy)	全国ポルフィリン代謝障害友の会 (さくら友の会) National Porphyrin Metabolic Disorder Friendship Association (Sakura Friendship Association)
POEMS 症候群サポートグループ POEMS Syndrome Support Group	アイザックス症候群りんごの会 Ringo Association for Isaacs Syndrome Patients
ミオパチー (筋疾患) の会オリーブ Society of Myopathy Olive	胆道閉鎖症の子どもを守る会 Association to Protect Children with Biliary Atresia
特定非営利活動法人 無痛無汗症の会トゥモロウ NPO Anhidrosis and Pain Free Society Tomorrow	特定非営利活動法人筋強直性ジストロフィー患者会 NPO Myotonic Dystrophy Patients' Group of Japan
富士市難病患者・家族連絡会 Fuji City Intractable Disease Patients and Families Group	ADSS1 ミオパチー患者家族会 ADSS1 Myopathy Patients Family Association