Press Release

European Federation of Pharmaceutical Industries and Associations (EFPIA Japan)
December 19, 2025

EFPIA Day - Patient Forum 2025
Joint Statement on Challenges in Improving Health Literacy and the Importance of Patient and Public Involvement (PPI)

Tokyo, Japan (December 19, 2025) – EFPIA Japan (Chairman: Takahiko Iwaya) announces today the release of a joint statement on the challenges in improving health literacy and the importance of patient and public involvement (PPI), in collaboration with the following participants:

- Yoshiyuki Majima, President, PanCAN Japan (NPO)
- Kaori Ikesaki, Representative, PPeCC (General Incorporated Association)
- Hiroshi Daikoku, Representative Director, Japan Patients Association for Intractable and Rare Diseases (JPA)
- Naomi Sakurai, Vice President, Japan Cancer Patient Association Federation
- Kazuhiro Nakayama, Professor of Nursing Informatics, St. Luke’s International University
- Takahiko Iwaya, President, EFPIA Japan

Patient Forum 2025 on EFPIA DAY, October 20, 2025

On October 20, 2025, EFPIA Japan hosted the Patient Forum 2025 in Tokyo, inviting representatives from various organizations, including patient groups, to discuss the barriers to improving health literacy and the importance of patient and public involvement (PPI). This joint statement summarizes the key agreements made during the forum.

Summary of Joint Statement

The forum participants agree on the need for the following actions based on recognition of current circumstances and the collaborative discussions through this “Patient Forum 2025” involving industry, government, academia, and patients to address the ongoing issues:

1. **Establishing an Environment to Support Shared Decision-Making Between Patients, Families, and Healthcare Professionals**
   Patient communities play a critical role in enabling patients to discern accurate information in an era of information overload. These communities should be recognized as social capital, and their significance must be widely promoted among healthcare professionals, policymakers, and society at large.
2. **Promoting Patient and Public Involvement in Healthcare**
   Patient involvement during policy formulation must be secured through institutional mechanisms. Going forward, participation should expand beyond specific disease areas to encompass a broader range of conditions.
3. **Improving Information Delivery and Accelerating Data Utilization**
   Advancing digitalization and utilization of healthcare information requires balancing use and protection, ensuring transparency and accountability, and building trust between system designers and patients/citizens. Permanent structures enabling public participation in these discussions are strongly recommended.

This statement advocates for:

- Correctly valuing innovation;
- Viewing healthcare not as a “cost” but as an investment in the future; and
- Fostering an inclusive approach where government, healthcare professionals, academia, patient organizations, citizens, and industry engage in dialogue.

Through these efforts, we aim to create an environment where patients and citizens actively participate in policy-making and make informed decisions with confidence—advancing the democratization of healthcare and promoting co-creation in healthcare.

About EFPIA Japan (http://efpia.jp/)

Established in April 2002, EFPIA Japan (http://efpia.jp/) represents 24 R&D-based European pharmaceutical companies operating in Japan. In 2024, combined sales from the member companies accounted for roughly 29.4% of the pharmaceutical market in Japan. The mission of EFPIA Japan is to “Contribute to healthcare and patients in Japan through the early introduction of innovation medicines and vaccines”. EFPPIA Japan aims to strengthen dialogue with decision-makers in order to improve Japanese healthcare for all.

About EFPIA, European Federation of Pharmaceutical Industries and Associations (http://www.efpia.eu)

EFPIA represents the biopharmaceutical industry operating in Europe. Through its direct membership of 37 national associations, 40 leading pharmaceutical companies and a growing number of small and medium-sized enterprises (SMEs), EFPIA’s mission is to create a collaborative environment that enables our members to innovation, discover, develop and deliver new therapies and vaccines for people across Europe, as well as contribute to the European economy.

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Joint Statement on Challenges in Improving Health Literacy and the Importance of Patient and Public Involvement (PPI)

EUROPEAN FEDERATION OF PHARMACEUTICAL INDUSTRIES AND ASSOCIATIONS (EFPIA JAPAN)

SIGNERS

Yoshiyuki Majima, President, PanCAN Japan (NPO)

Haruka Ikezaki, Representative, PPeCC (General Incorporated Association)

Hiroshi Oguro, Representative Director, Japan Patients Association for Intractable and Rare Diseases (JPA)

Naomi Sakurai, Vice President, Japan Cancer Patient Association Federation

Kazuhiro Nakayama, Professor of Nursing Informatics, St. Luke’s International University

Takahiko Iwaya, President, EFPIA Japan

Date: October 20, 2025, EFPIA DAY PATIENT FORUM 2025

PATIENT FORUM 2025

The Patient Forum, organized by EFPIA Japan, was launched in 2024 to ensure that patients’ voices are reflected in healthcare policy from the perspective of **Patient Engagement**. On October 20, 2025, stakeholders from diverse sectors convened in Tokyo under the theme:

"Barriers to Improving Health Literacy and the Importance of Patient and Public Involvement (PPI)".

Based on discussions aimed at recognizing current challenges and identifying solutions through collaboration among industry, government, academia, and patient organizations, we hereby issue this joint statement to share the following common understanding and call for action.

1. Establishing an Environment to Support Shared Decision-Making Between Patients, Families, and Healthcare Professionals

Information in healthcare should serve as a tool for decision-making. It is essential to present patients with options and enable them to understand the benefits and risks of each. Internationally, the right to make decisions is recognized as a Human Right, and failure to provide options is considered a violation of that right.

In Japan, support for skills related to decision-making—such as accessing, understanding, evaluating, and utilizing information—is insufficient. Developing supportive tools such as decision aids is an urgent priority. Systematic education on decision-making, through collaboration among schools, healthcare settings, and patient organizations, is needed.

The forum highlighted that experiences and shared information obtained through patient organizations serve as "living information" that is highly valuable for real-world decision-making. Patient communities play a critical role in enabling patients to discern accurate information in an era of information overload. These communities should be recognized as social capital, and their significance must be widely promoted among healthcare professionals, policymakers, and society at large

2. Promoting Patient and Public Involvement in Healthcare

Institutionalizing PPI ensures that patients' and citizens' voices are reflected in healthcare system design, contributing to a society that embraces both health and life with illness. Patient representatives shared examples where participation in policy design helped bridge gaps between systems and real-world practice.

PPI is indispensable across all stages of healthcare, drug development, and policy-making. Particularly, patient involvement during policy formulation must be secured through institutional mechanisms. Going forward, participation should expand beyond specific disease areas to encompass a broader range of conditions.

3. Improving Information Delivery and Accelerating Data Utilization

Both pull-based (search) and push-based (notification) systems are essential for patients to proactively access healthcare information. For example, in clinical trials, ensuring patients have direct access to information is critical for informed choices.

Currently, Japan’s Pharmaceutical and Medical Device Act does not explicitly designate patients as recipients of information, requiring provision through healthcare professionals. Future legal revisions and guidelines must clarify mechanisms for direct patient access, incorporating patient input.

Advancing digitalization and utilization of healthcare information requires balancing use and protection, ensuring transparency and accountability, and building trust between system designers and patients/citizens. Permanent structures enabling public participation in these discussions are strongly recommended.

Conclusion

To realize a society where everyone can make decisions true to themselves, it is essential to broaden patient and public involvement and establish robust frameworks for healthcare information. This statement advocates for:

- Correctly valuing innovation
- Viewing healthcare not as a “cost” but as an investment in the future
- Fostering an inclusive approach where government, healthcare professionals, academia, patient organizations, citizens, and industry engage in dialogue

Through these efforts, we aim to create an environment where patients and citizens actively participate in policy-making and make informed decisions with confidence—advancing the democratization of healthcare and promoting co-creation in healthcare.

【Organizations Participating in this Joint Statement】

■PanCan Japan(Non-Profit Organization)（https://pancan1.org/index.php)

PanCAN Japan was established in 2006 as the Japanese branch of the U.S.-based non-profit PanCAN. Its mission is to eradicate pancreatic cancer by actively supporting research initiatives and collaborating with other patient advocacy groups, healthcare professionals, government agencies, and related companies. PanCAN Japan conducts awareness campaigns, organizes study sessions to address challenges in outpatient treatment, and works to ensure that pancreatic cancer patients and their families receive safe and effective care. United under the slogan "Eradicate Pancreatic Cancer", PanCAN Japan strives to build a stronger, more supportive community for patients and families nationwide.

■PPeCC (General Incorporated Association) (https://ppecc.jp/company/)

PPeCC aims to create a society where people can confidently say, "It's okay to live with illness." The organization connects patients, families, patient groups, companies, and local communities through a wide range of activities, including operating the PPeCC Salon (a free online community), hosting events and study sessions, and engaging in advocacy and awareness initiatives. PPeCC has led projects such as "Voice Production", which transforms patient voices into actionable insights for developing treatments, medicines, and services from the patient's perspective. The organization also works on policy proposals, employment support, and other initiatives to improve quality of life for people living with illness.

■St. Luke's International University - Nursing Informatics

(https://university.luke.ac.jp/faculty_and_research/informatics.html)

The Nursing Informatics program at St. Luke's International University focuses on decision-making support, positive coping strategies, and building supportive networks and social capital. Through social research involving patients, citizens, and healthcare professionals, the program examines whether individuals can make informed decisions, identifies barriers, and evaluates the adequacy of available support. Nursing Informatics at St. Luke's is defined as a discipline that ensures appropriate access, understanding, evaluation, and utilization of information for decision-making and action.

■Japan Cancer Patient Association Federation (General Incorporated Association) (https://zenganren.jp/)

Established in May 2015, the Japan Cancer Patient Association Federation is a coalition of cancer patient organizations across Japan. Its mission is to improve cancer care and create a society where people can live securely even after a cancer diagnosis. The federation promotes collaboration among patient groups, addresses challenges in treatment, care, and daily life, and engages in activities with diverse stakeholders to advance cancer care and patient well-being.

■Rare Cancers Japan（https://rarecancersjapan.org/）

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.

■Japan Patients Association for Intractable and Rare Diseases (JPA) (https://nanbyo.jp/)

JPA is a nationwide organization comprising patient groups for rare and chronic diseases. Its goal is to resolve social challenges faced by patients and families while promoting understanding among citizens. JPA advocates for legislative and administrative reforms through parliamentary petitions, raises public awareness of rare diseases, and facilitates patient and family networking. It also operates patient support programs under the Ministry of Health, Labor and Welfare, conducts training, and promotes international collaboration.

■European Federation of Pharmaceutical Industries and Associations（EFPIA Japan） (http://efpia.jp/)

Founded in April 2002, EFPIA Japan represents 24 European research-driven pharmaceutical companies operating in Japan. In 2024, combined sales from the member companies accounted for roughly 29.4% of the pharmaceutical market in Japan. EFPIA Japan’s mission is to contribute to Japanese healthcare and patients by ensuring the early introduction of innovative medicines and vaccines. The organization seeks to strengthen dialogue with policymakers to advance healthcare in Japan.

[Patient Organizations Supporting This Joint Statement]

Japan Federation of Cancer Patient Groups (49 organizations in total)	
一般社団法人 ＣＳＲプロジェクト Cancer Survivors Recruiting Project	サバイバーナースの会「ぴあナース」 Survivor Nurse Association “Peer Nurses”
特定非営利活動法人 GISTERS GISTERS（NPO for GIST patients）	小児脳腫瘍の会 Pediatric Brain Tumor Network of Japan
NPO 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 ＨＯＰＥ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 あいおぷらす 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 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

Rare Cancer Japan (22 organizations in total)	
• Pediatric and AYA (Adolescent and Young Adult) Cancer	
小児脳腫瘍の会 Pediatric Brain Tumor Network of Japan	「小児脳幹部グリオーマ」シンポジウム開催実行委員会 DIPG Symposium Organizing Committee
「すくすく」網膜芽細胞腫の家族の会 Family support group for Retinoblastoma (Sukusuku)	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 Patient Family Group	神経芽腫の会 Neuroblastoma Family Association of Japan
一般社団法人 トルコキキョウの会 General Incorporated Association Torukokikyou	小児脳幹部グリオーマの会 Child Brain Stem Glioma Network
Other Rare Cancer	
NPO 法人 パンキャンジャパン（神経内分泌腫瘍患者会） Neuro-Endocrine Tumor Patients Association (PanCAN Japan)	メラノーマ患者会 Over The Rainbow Melanoma Patients Association – Over The Rainbow
NPO 法人 キュアサルコーマ Cure Sarcoma	中皮腫・アスベスト疾患・患者と家族の会 Japan Association Mesothelioma and Asbestos Related Disease Victims and their Families
NPO 法人 GISTERS GISTERS（NPO for GIST patients）	NPO 法人中皮腫サポートキャラバン隊 Mesothelioma Support Caravans
肉腫（サルコーマ）の会 たんぽぽ Japan Sarcoma Patients Network “TANPOPO”	頭頸部がん患者と家族の会 Nicotto（ニコット） Head and Neck Cancer Patients and their families Association ‘’Nicotto’’
NPO 法人脳腫瘍ネットワーク Japan Brain Tumor Alliance (JBTA)	シェスタ会 The Siesta
胸腺腫・胸腺がん患者会 ふたつば FUTATSUBA – Thymoma/Thymic Carcinoma Patient Support Group	ROS1 ポジティブ♪ ROS1 Positive♪
腹膜偽粘液腫患者支援の会 PMP patients’ network of Japan	肺がん HER2「HER HER」 Lung Cancer HER2 ‘’HER HER’’

Japan Patients Association (102 organizations in total)	
Regional Rare Disease Associations	
一般財団法人 北海道難病連 Hokkaido Federation of Intractable Diseases	NPO 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	NPO 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	NPO 法人 滋賀県難病連絡協議会 NPO Shiga Prefecture Council for Intractable Diseases
NPO 法人 宮城県患者・家族団体連絡協議会 Miyagi Prefecture Council of Patient and Family Groups	NPO 法人 京都難病連 NPO Kyoto Federation of Intractable Diseases
NPO 法人 秋田県難病団体連絡協議会 Akita Prefecture Council of Intractable Disease Organizations	NPO 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	NPO 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	NPO 法人 高知県難病団体連絡協議会 Kochi Prefecture Council of Intractable Disease Organizations
NPO 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 NPO 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	熊本難病・疾病団体協議会 Kumamoto Council of Intractable Disease and Disease Organizations
長野県難病患者連絡協議会 Nagano Prefecture Council of Patients with Intractable Diseases	NPO 法人 大分県難病・疾病団体協議会 NPO Oita Prefecture Council of Intractable Disease and Disease Organizations
NPO 法人 岐阜県難病団体連絡協議会 Gifu 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
NPO 法人 静岡県難病団体連絡協議会 NPO Shizuoka Prefecture Council of Intractable Disease Organizations	
Disease-specific Organizations	
NPO 法人 IBD ネットワーク NPO IBD Network	日本 AS 友の会 Japan Ankylosing Spondylitis Club（JASC）
下垂体患者の会 Pituitary Patients Association	一般社団法人 日本 ALS 協会 Japan ALS Association (JALSA)
再発性多発軟骨炎（RP）患者会 Relapsing Polychondritis (RP) Patients Association	NPO 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
一般社団法人全国筋無力症友の会 Japan Myasthenia Gravis Association	日本肝臓病患者団体協議会 Japan Hepatitis Council
一般社団法人 全国膠原病友の会 National Collagen Disease Friendship Association	NPO 法人 日本マルファン協会 NPO Japan Marfan Association
全国 CIDP サポートグループ National CIDP Support Group	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 全国心臓病の子どもを守る会 National Association for Protecting Children with Heart Disease	ベーチェット病友の会 Behcet's Disease Tomo-no-kai Patients' Circle
一般社団法人 全国腎臓病協議会	もやもや病の患者と家族の会

National Kidney Disease Council	Moyamoya Disease Patients and Families Association
NPO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	NPO法人 日本オスラー病患者会 NPO Japan Osler's Disease Patients 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	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 全国パーキンソン病友の会 National Parkinson's Disease Friendship Association	近畿つぼみの会 Kinki Tsubomi no Kai
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)	特定非営利活動法人 筋強直性ジストロフィー患者会 Specified Nonprofit Organization Myotonic Dystrophy Patients' Association
側弯症患者の会（ほねっと） Scoliosis Patients' Association (HONETTO)	封入体筋炎（IBM）患者会（ポピーの会） Inclusion Body Myositis (IBM) Patients' Association (Poppy Association)
Associate Member Organizations	
認定NPO法人 アンビシャス NPO Ambitious	日本網膜色素変性症協会 Japan Retinitis Pigmentosa Society
SBMAの会（球脊髄性筋萎縮症） Spherospinal Muscular Atrophy Association	ＰＸＥ Ｊａｐａｎ（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)
NPO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)	スティッフパーソンみんなの会 Association of Stiff Persons Patients
公益財団法人 がんの子どもを守る会 Children's Cancer Association Japan	膵島細胞症患者の会 Islet Cell Disease Patients Association
NPO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：NPO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)	ギラン・バレー症候群患者の会 Guillain-Barré Syndrome Patients Association
シルバーラッセル症候群ネットワーク Silver Russell Syndrome Network	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
NPO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	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
一般社団法人 先天性ミオパチーの会 Congenital Myopathy Association	サルコイドーシス友の会 Sarcoidosis Friendship Association
高安動脈炎友の会（あけぼの会） Takayasu Arteritis Friendship Association (Akebonokai)	NPO法人 境を越えて NPO Beyond Boundaries
竹の子の会（プラダー・ウイリー症候群児・者親の会） Takenoko no Kai (Association of Parents of Children and Persons with Prader-Willi Syndrome)	みやぎ化学物質過敏症の会〜ぴゅあぃ〜 Miyagi Chemical Substance Hypersensitivity Association ~PYUAY
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)	一般社団法人 ピーペック PPeCC
NPO法人 難病支援ネットジャパン NPO Intractable Disease Support Network Japan	NPO法人 両育わーるど NPO Ryoyuiku World

NPO 法人 新潟難病ネットワーク NPO Niigata Network for Intractable Diseases	NPO 法人 線維筋痛症友の会 NPO Fibromyalgia Friendship Association
認定 NPO 法人 日本 IDDM ネットワーク Certified NPO Japan IDDM Network	SMA（脊髄性筋萎縮症）家族の会 SMA (Spinal Muscular Atrophy) Family Association
日本ゴーシェ病の会 Association of Gaucher Disease Patients in Japan	MECP2 重複症候群患者家族会 MECP2 Duplication Syndrome Patient Family Association
NPO 法人 日本プラダー・ウイリー症候群協会 NPO Prader-Willi Syndrome Association Japan (PWSA Japan)	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)
NPO 法人 PADM 遠位型ミオパチー患者会 NPO PADM (Patients Association for Distal Myopathy)	アイザックス症候群りんごの会 Ringo Association for Isaacs Syndrome Patients
POEMS 症候群サポートグループ POEMS Syndrome Support Group	胆道閉鎖症の子どもを守る会 Association to Protect Children with Biliary Atresia
ミオパチー（筋疾患）の会オリーブ Society of Myopathy Olive	ADSS1 ミオパチー患者家族会 ADSS1 Myopathy Patients Family Association
NPO 法人 無痛無汗症の会トゥモロウ NPO Anhidrosis and Pain Free Society Tomorrow	NPO 法人筋痛性脳脊髄炎の会 NPO Association for Myalgic Encephalomyelitis
富士市難病患者・家族連絡会 Fuji City Intractable Disease Patients and Families Group キャッスルマン病患者会 Castleman's Disease Patients Group	一般社団法人甲状線眼症の医療を前進させる患者の会 General Incorporated Association: Patients' Group for Advancing Medical Care for Thyroid Eye Disease ムコネット Twinkle Days MukoNet Twinkle Days