



Pharma and ESG

The patient perspective

The views of 701 patient groups



Contents

	Page
Introduction	1
Key findings	5
The types of support patient groups seek from pharma on ESG	18
I. Developing pharma/patient-group relations in the context of ESG	20
II. Issues of importance to patient-groups around pharma's ESG agendas	23
Scores and rankings of 15 big pharma companies, 2024, as assessed by respondent patient groups familiar with the companies	27
Scores and rankings of 15 big pharma companies, 2024, as assessed by respondent patient groups working with the companies	30
Profiles of the 15 big pharma companies, 2024	33
Appendices:	
I. Profiles of respondent patient groups, 2024	64
II. List of respondent patient groups wishing to be attributed, 2024	66

Published by PatientView Ltd

Contact details:

Registered office: One Fleet Place, London, EC4M 7WS, UK

Tel: +44-(0)1547-520-965

Email: report@patient-view.com

Registered in England, Number: 3944382

Data protection registration number: Z7133076

VAT registration number: GB-760-985-885

Introduction

Environmental, Social and Governance (ESG) was a term first introduced in 2004 by the United Nations, to encourage companies to consider issues of sustainability in their investment decisions. Since then, Socially Responsible Investing (SRI) emerged as a way for investors to align their portfolios with ESG values, compelling more and more companies, including pharma, to adopt in-house ESG strategies.

However, the context and application of ESG has changed over the past decade. In 2025, ESG is not as pivotal an issue due to several factors, not least the political tensions associated with ESG, the perceived rigidity of EU legislation and below-expected returns on ESG investment.¹ The combination of these changes has dampened investor enthusiasm, which is striking because it was the investment community that drove companies to adopt ESG practices in the first place. *(See box at end of introduction on page four, for further context.)*

Why this PatientView survey?

In the light of these details, what is the significance of this PatientView ESG survey? For patients and patient groups, ESG has taken on a unique dynamic, which is making some of them maintain (or even grow) the enthusiasm that investors are losing. PatientView is now in its third year of research into assessing patient perspectives of pharma's ESG activities.

- In June 2022, PatientView published its first examination of patient-group views of pharma ESG. The initial aim was to determine the levels of interest and awareness patient groups worldwide had in the subject (as part of a November 2021-February 2022 survey on pharma's corporate reputation). Over half (55%) of the 1,500 respondents to the survey claimed to have no knowledge about pharma's ESG activities, although 45% did. Among the remaining respondents, a small number of patient groups claimed not to care about pharma's ESG, being preoccupied with more immediate and distressing medical illness. Others that did know about pharma ESG felt that the targets and activities should be redefined for the benefit of patients and the public.
- The second piece of research — published in November 2023 — was a dedicated survey about ESG. 832 patient-groups responded, from 79 countries and 173 different therapy areas — indicating an increased interest in the topic of ESG. The survey sought to define what ESG factors pharma might pursue in accordance with patients and patient-group interests.
- Now in February 2025, this latest research, for the first time seeks to quantify patient opinions on the ESG practices of the pharma industry as a whole and of 15 big-pharma companies. The analyses has focused on big pharma, which currently owns a more developed and detailed ESG agenda— although there are clearly some smaller pharma companies active in the area. A questionnaire was developed using the previous PatientView research as an evidence base, together with input from several pharma companies. This insight into patient-group priorities for corporate ESG resulted in a set of 8 key indicators. These were formulated to measure companies' effectiveness at ESG from a patient perspective. The subsequent

¹ <https://www.reuters.com/sustainability/sustainable-finance-reporting/sustainable-funds-market-inflows-halve-esg-falls-out-favour-2025-01-27/>

October to November 2024 ESG survey collected responses from 701 patient groups worldwide, from 74 countries and 201 specialties. The results should go some way to defining and standardising how pharma can measure their impact on patient society, as required by new EU legislation (double materiality). These eight indicators also overlap with efforts made by specific pharma companies seeking to develop a patient-centric framework for ESG, although corporate approaches vary.²

About the patient perspective on ESG

Patient groups do have differing perspectives and interests (compared with investors) about pharma ESG, often related to their own medical situation. According to a report by S&P³, the more relevant issues that impact materiality among patients and patient groups are access and affordability, or customer health and safety. Environmental factors are generally less important than social factors in the healthcare industry. This finding was also substantiated in the PatientView survey.

The 2025 report is centred around eight key indicators:



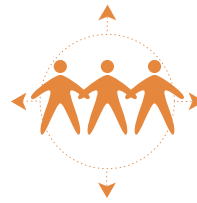
INDICATOR 1: COMMUNICATION

Companies “Best” at communicating their ESG activities SPECIFICALLY to patient groups (beyond just publishing ESG reports on their company website).



INDICATOR 2: ACCOUNTABILITY TO PATIENTS

Companies “Best” at listening to patients and patient groups’ views on ESG issues.



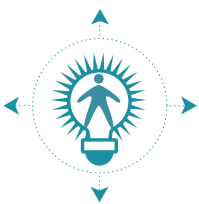
INDICATOR 3: PATIENT ENGAGEMENT

Companies “Best” at including patient group ESG views in their ESG strategies.



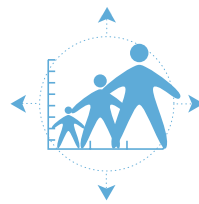
INDICATOR 4: SUPPORT TO PATIENT GROUPS

Companies “Best” at supporting patient groups in their own ESG activities.



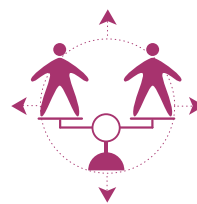
INDICATOR 5: PUBLIC CLARITY OF PURPOSE

Companies “Best” at communicating their ESG goals to patients, patient groups and the general public.



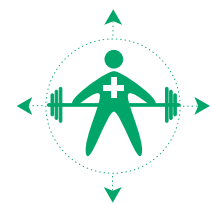
INDICATOR 6: TRANSPARENT REPORTING

Companies “Best” at communicating performance at achieving their ESG goals to patients, patient groups, and the general public.



INDICATOR 7: EQUITY AND ACCESS

Companies “Best” at addressing health inequalities in patient group countries (from early-stage R&D, to patient access to medicines).



INDICATOR 8: STRENGTHENING HEALTHCARE SYSTEMS

Companies “Best” at ensuring their ESG activities strengthen healthcare systems of patient group countries.

2 <https://patientengagement.synapseconnect.org/resources/integrating-patient-perspectives-into-sustainability-strategies-2024-white-paper>
3 https://www.spglobal.com/_assets/documents/ratings/research/101568351.pdf

For example, PatientView research finds that patient groups dislike long drug-distribution chains, not only because of the environmental damage done by transportation, but because of the possible delays to drug supply and increased likelihood of medicine shortages.⁴ Therefore, even though companies may be generally compliant to their declared ESG standards, this might not translate into an improved relationship with patients and patient groups, unless the patient as a stakeholder sees a personal benefit from corporate actions on ESG—which is why the patient perspectives outlined in the latest PatientView report are important.

Words of caution interpreting results

As discussed previously, there are differing attitudes to the integrity of ESG, specifically when comparing Western Europe and the USA. This variation is evident from the geographic distribution of respondents to PatientView's 2025 ESG survey, which attracted fewer US-based patient groups compared with other PatientView research. The changing ESG landscape means that pharmaceutical companies reading this PatientView report need to take account of:

- ➔ The country headquarters of the patient groups, which will have impact on their perspectives, particularly the socio-political dialogue in that country.
- ➔ Given the variation of ESG legislation worldwide pharmaceutical companies cannot take a singular approach toward their ESG activities, with respect to patient groups. Instead, their ESG strategies must be flexible to cope with the shifting ESG terrain.

⁴ PatientView, Pharma and ESG, November 2023 p.29

The changing ESG landscape

According to Global Data in its end-2024 poll “the proportion of respondents who feel that ESG is the theme that will most impact their business in the next 12 months is at one of its lowest points for at least three years and that ESG ranks at its lowest-equal compared to other themes over the same period.”¹

According to Reuters in 2024: “Money flowing into global sustainable funds shrank by half in 2024 and in Europe closures of such funds outpaced new launches.”²

Several factors have influenced the ESG landscape undermining investor and corporate enthusiasm.

Increased mandatory regulation

In January 2023, the EU required companies to report on their ESG compliance, according to set standards, known as European Sustainability Reporting Standards (ESRS). In 2025, the EU hardened up the ESRS by demanding companies not only inform how sustainability issues might create financial risks for the company (**financial materiality**), but also the company’s own impacts, both direct and indirect, on people and the environment (**impact materiality**). The concept is known as double materiality, and gives companies a formal mechanism for showing their ESG compliance and avoid greenwashing (making unverifiable claims about improvements in sustainability)³

Regardless of the reduced investor interest (primarily because of increased regulation), that same regulation now has a legal basis and framework for including the views of patients and patient groups.⁴

Anti-ESG sentiments in the USA

In the USA, ESG is a controversial partisan political issue, which means the very idea of ESG is resisted by some camps, while lauded by others. The USA has seen a recent rising tide of anti-ESG sentiment, which could be reinforced by the 2024 election of ESG-sceptic Donald Trump as US president. To compound this, ESG legislation is largely considered a state issue, not a federal one. For example, 15 states in the USA have now introduced anti-ESG legislation.⁵ Thus in the USA, ESG legislation is potentially unpredictable because it is conducted at local levels and heavily impacted by uncontrollable political events.

1 <https://www.investmentmonitor.ai/news/esg-plummets-among-business-priorities-amid-global-upheaval/>

2 <https://www.reuters.com/sustainability/sustainable-finance-reporting/sustainable-funds-market-inflows-halve-esg-falls-out-favour-2025-01-27/>

3 <https://ec.europa.eu/newsroom/fisma/items/754701/en>

4 https://viewpoint.pwc.com/dt/us/en/pwc/in_the_loop/assets/navesgitl07nov23.pdf

5 <https://about.bnef.com/blog/anti-esg-crusade-in-us-sweeps-15-states-with-more-laws-in-works/>

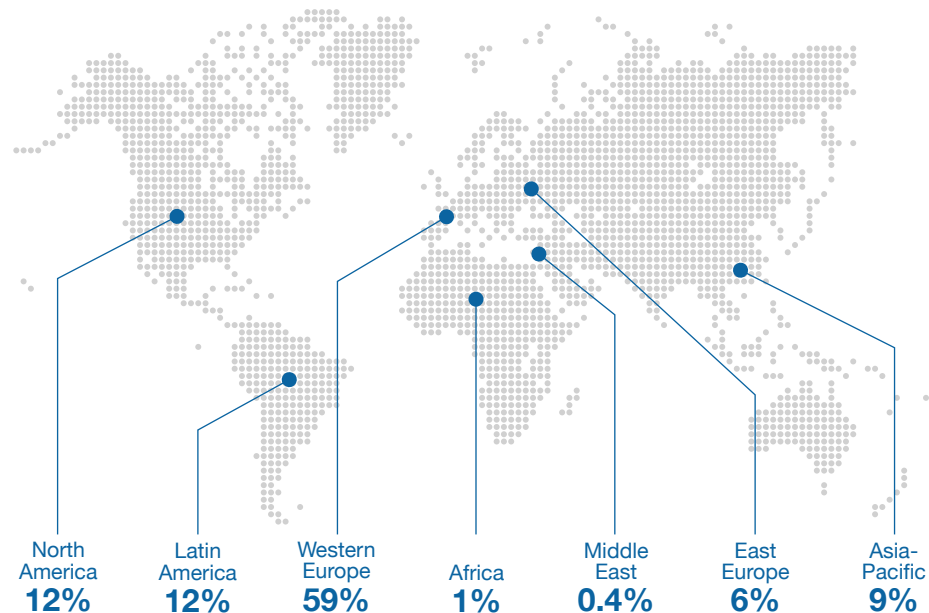
Key findings

For the past three years, PatientView has conducted an annual survey of patient groups worldwide, to evaluate these organisations' perspectives of pharma's reputation regarding ESG practices. The latest September-November 2024 ESG survey attracted responses from 701 patient groups globally, the profiles of which can be found in Appendix I. Patient groups which were happy to be named as participants in this survey can be found in Appendix II. The respondent patient groups represented diverse conditions and were based in 74 countries across the around the world.

Geographic location of respondent patient groups

Percentage of total, N=701

One respondent did not specify their country headquarters



Both quantitative and qualitative patient-group feedback was collected in the ESG survey on the following:

- ➔ The importance of pharma ESG policies and activities to patient groups.
- ➔ The effectiveness of individual pharma companies at ESG activities according to eight key indicators – *defined by both patient groups and pharma.*
- ➔ How patient groups wish be supported by pharma in the context of corporate agendas for ESG.

Profiles of the 15 big pharma companies, 2024

Indicators for pharma and ESG:

- 1 Communication
- 2 Accountability
- 3 Patient engagement
- 4 Support
- 5 Public clarity
- 6 Transparent reporting
- 7 Equity and access
- 8 Strengthening healthcare

1st page: company profiles and scores

- The number of respondent patient groups **familiar**, and **working**, with the company, 2024.
- The profile of the respondent patient groups **familiar** with the company (the number of patients reached; country of headquarters; specialties; and geographic remit), 2024.
- The types of relationships that the company had with its respondent patient-group **partners**, 2024.
- Company performance at the individual indicators of corporate reputation, 2024—as assessed by respondent patient groups **familiar**, and **working**, with the company.
- Competitors' relationships in 2024 with the company's respondent patient-group **partners**.

2nd page: company rankings

- Company **global** rankings for each of the indicators—as assessed by respondent patient groups familiar, or working, with the company, 2024.
- Company **Western Europe** rankings for each of the indicators—as assessed by respondent patient groups familiar, or working, with the company, 2024.
- Company **USA** rankings for each of the indicators—as assessed by respondent patient groups familiar, or working, with the company, 2024.

Appendix I

- Specialties of respondent patient groups
- Country headquarters of respondent patient groups
- Geographic reach of respondent patient groups

Specialties of respondent patient groups, 2024

Number of respondents, N= 701

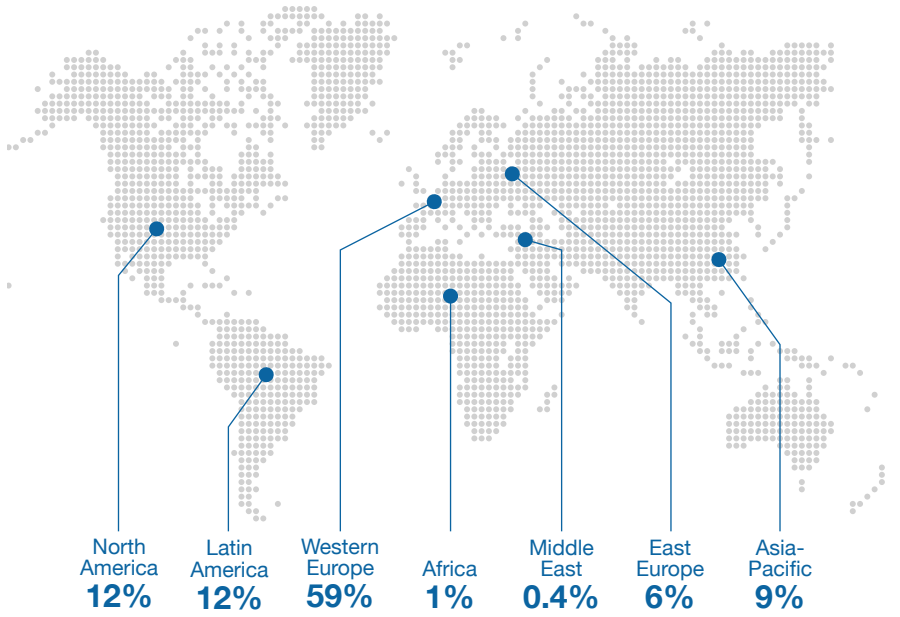
Respondent patient groups may fall into more than one category of speciality

Main therapeutic categories: Percentage of respondent patient groups

	%		%
Allergic conditions	1.4	Medical research	0.6
Autoinflammatory diseases	0.3	Men's health	2.4
Bleeding disorders	2.3	Mental health	3.9
Blood disorders	1.1	Musculoskeletal conditions	0.7
Bone conditions	1.9	Neurological conditions	13.1
Cancer	20.5	Neurodegenerative diseases	6.9
Cardiovascular diseases	1.1	Neuromuscular conditions	1.9
Carers, family, friends	1.0	Older people	0.6
Cerebrovascular diseases	1.0	Other autoimmune conditions	1.4
Children's health	1.9	Other circulatory conditions	0.1
Chronic diseases in general	0.6	Other disabilities	0.1
Endocrine conditions	5.5	Patient advocacy	1.4
Gastrointestinal conditions	2.7	Patient education	0.9
General health	3.0	Patient safety	0.1
Gynaecological conditions	0.7	Rare diseases	20.1
Hearing loss	0.3	Reproductive health	0.3
Heart conditions	2.0	Respiratory conditions	6.9
Hepatitis	1.1	Rheumatic diseases	6.2
HIV/AIDS	4.9	Skin conditions	3.9
Immune disorders	0.9	Spinal disorders	0.1
Infectious diseases	0.7	Transplants	1.4
Kidney diseases	3.0	Urinary conditions	0.9
Learning disorders	0.4	Visual impairment	2.3
Liver diseases	1.9	Women's health	5.0

Regional/country headquarters of respondent patient groups

Percentage and number of respondents, N= 701
 One respondent did not specify their country headquarters

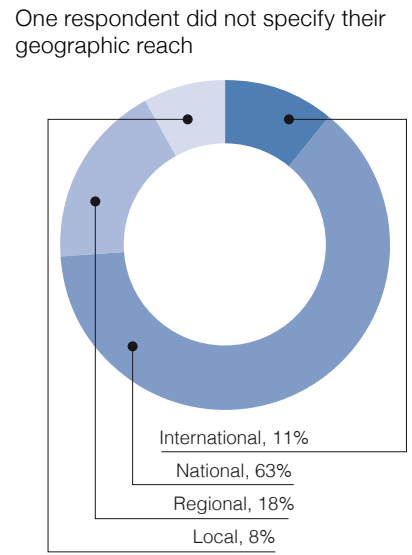


Country	No
Albania	1
Argentina	5
Australia	12
Austria	13
Belgium	35
Brazil	34
Bulgaria	1
Canada	37
Chile	2
Colombia	10
Costa Rica	3
Croatia	4
Cyprus	5
Czech Republic	4
Democratic Republic of Congo	1
Denmark	15
Dominican Republic	4
Ecuador	1
Egypt	1
El Salvador	1
Estonia	1
Ethiopia	1
Finland	14
France	34
Germany	29

Country	No
Greece	21
Guatemala	1
Honduras	1
Hong Kong	1
Hungary	7
Iceland	1
India	7
Iraq	1
Ireland	2
Israel	2
Italy	54
Japan	12
Kenya	1
Korea	5
Kosovo	1
Latvia	1
Lithuania	1
Malaysia	2
Malta	1
Mexico	11
Nepal	2
Netherlands	22
New Zealand	6
Nicaragua	1
Nigeria	1

Geographic reach of respondent patient groups

Percentage of respondent patient groups, N=701
 One respondent did not specify their geographic reach



Country	No
Norway	10
Panama	6
Philippines	5
Poland	16
Portugal	22
Puerto Rico	2
Romania	2
Senegal	1
Serbia	2
Singapore	1
Slovenia	3
South Africa	2
Spain	52
Sweden	37
Switzerland	7
Taiwan	12
Thailand	1
Turkey	9
UK	28
Uruguay	1
USA	44
Venezuela	1
Zambia	1
Zimbabwe	2

Appendix II

List of respondent patient groups willing to be attributed

List arranged in alphabetical order of respondent patient groups' countries—and within each country, in alphabetical order of patient-group names/acronyms

ALBANIA

Institute for Health, Social Policy and Research Development / Stop AIDS Association Albania

ARGENTINA

APAEH – Huntington Argentina
Asociación de Fiebre Mediterránea Familiar y Autoinflamatorias de Argentina

AUSTRALIA

Brisbane Brain Tumour Support Group
Crohn's & Colitis Australia
Cystic Fibrosis Queensland
Good-Works Advocacy
ITP Australia and New Zealand
Lung Foundation Australia
Neuroblastoma Australia
NeuroEndocrine Cancer Australia
Psoriasis Australia Inc
Transplant Australia

AUSTRIA

DEBRA Austria
FHchol Austria
Forum Seltene Krankheiten
Global Allergy & Airways Patient Platform (GAAPP)
Hepatitis Hilfe Österreich (HHÖ) – Plattform Gesunde Leber
Lobby4kids – Kinderlobby
Multiples Myelom Selbsthilfe Österreich
ÖGSHT – Österreichische Gesellschaft für Schädel-Hirn-Trauma
Verein PULSHIV

BELGIUM

AmyBel asbl – Amyloidosis Association Belgium
Association ELA – Association Européenne contre les Leucodystrophies
Belgian Brain Council
BOKS vzw
Borstkanker Kempen vzw
CLAIR asbl
CMP Vlaanderen vzw
COPD vzw

EMHA – European Migraine & Headache Alliance

EU-PFF – European Pulmonary Fibrosis Federation

Europa Uomo

Ligue Cardiologique Belge

Ligue Huntington Francophone Belge (LHFB) asbl

Liver Patients International (LPI)

Melanoompunt vzw

MS-Liga Vlaanderen vzw

Neovida vzw

OKRA vzw

RA Liga vzw

Samen na Borstoperatie

Stoma-Actief

Think Blue Vlaanderen vzw

Vlaamse Vereniging voor Spondyloarthritis (VVSA) vzw

VMCP – Vereniging voor mensen met chronische pijn

vzw NET & MEN Kanker België

BRAZIL

ABEM – Associação Brasileira de Esclerose Múltipla

ABPAR – Associação Brasileira de Amiloidose Hereditária Associada à Transtirretina

ABRACCIA – Associação Brasileira de Combate ao Câncer Infantil e Adulto Rua Visconde de Inhaúma

ABRAMI – Associação Brasileira de Miastenia

ACDR & ACAMU – Associação Catarinense de Doenças Raras

AFAG – Associação dos Familiares, Amigos e Portadores de Doenças Graves

ALAMBRA – Associação dos Portadores de Linfangioleiomiomatose do Brasil

Aliança Distrofia Brasil (ADB)

AMAVI Raras – Associação Maria Vitória de Doenças Raras e Crônicas

AMUCC – Associação Brasileira de Portadores de Câncer

APAR-SC – Associação dos Pacientes Renais de Santa Catarina

Associação dos AVCistas

Associação Nossa Casa de Apoio à Pessoas com Câncer

ATERR – Associação de Travestis e Transexuais do Estado de Roraima

Casa Hunter

DII Brasil – Associação Nacional dos Portadores de Doenças Inflamatórias Intestinais

Febrax – Federação Brasileira das Associações de Alzheimer

Fibrocis – Sociedade de Assistência à Fibrose Cística

Grupo Hepato Certo de Apoio a Portadores de Hepatite C

Grupo Pela VIDDA do Rio de Janeiro (GPV-RJ)

IGCC – Instituto de Governança e Controle do Câncer

INAME – Instituto Nacional da Atrofia Muscular Espinhal

Instituto Benjamin Constant (IBC)

Instituto Dé Mendonça – Lúpus Care

Instituto Nacional de Nanismo (INN)

Instituto Oncoguia

PSORIERJ – Associação de Amigos e Portadores de Psoríase do Estado do Rio de Janeiro

BULGARIA

Българска асоциация по Хемофилия

CANADA

ACCÉSSS – Alliance des communautés culturelles pour l'égalité de la santé et les services sociaux

Allergy Canada

Asthma Canada

CACTUS Montréal

Canadian Addison Society

Canadian Alopecia Areata Foundation (CanAAF)

Canadian Council of the Blind (CCB)

Canadian MPN Network (CMPNN) Patient Advocacy

CANFib (Canadian Women with Fibroids) NPO

Cure SMA Canada

Déjouer les allergies
 Diabète Drummond
 Dotty Nicholas Sickle Cell Scholarship Fund Association
 Fighting Blindness Canada (FBC)
 Lupus Ontario
 Melanoma Canada
 Mood Disorders Society of Canada (MDSC)
 MPN Ontario Patient Support
 PKD Foundation of Canada
 Préma-Québec
 Rethink Breast Cancer
 Schizophrenia Society of Canada (SSC)
 Scleroderma Canada
 Société canadienne d'urticaire chronique (CSPA)
 Thyroid Federation International (TFI)

CHILE

Fundación Cáncer Vida
 Fundación Me Nuevo

COLOMBIA

Asociación de Usuarios
 Corporación Luz Rosa
 FIQUIRES – Fundación Colombiana para la Fibrosis Quística y Enfermedades Respiratorias
 Fundación Debra Colombia
 Fundación Fundem
 Fundación Más Allá de la Distrofia (Fundación MADI)
 Fundación SENOSama
 Liga Colombiana de Hemofílicos y Otras Deficiencias Sanguíneas (Colhemofílicos)
 OICA Cáncer – Observatorio Interinstitucional de Cáncer de Adultos

COSTA RICA

AENDO-CR – Asociación Costarricense de Ayuda a Pacientes con Endometriosis
 APRONEP-er – Asociación Pro Niños con Enfermedades Progresivas Raras

CROATIA

Hrvatska Liga Protiv Raka (HLPR)
 KUZ – Koalicija udruga u zdravstvu
 MS TIM Hrvatska
 Nismo Same – Udruga žena oboljelih i liječenih od raka

CYPRUS

Europa UOMO Cyprus Λευκωσία
 Σύνδεσμος Πνευματοπαθών Κύπρου ΣύΠεΚ

CZECH REPUBLIC

Aliance žen s rakovinou prsu
 Česká společnost AIDS pomoc (ČSAP), z. s.
 Pacienti IBD z.s.
 ROZKOŠ bez RIZIKA, z.s.

DEMOCRATIC REPUBLIC OF CONGO

EPIH/SOS Hépatites RD Congo

DENMARK

SINDs Pårørende
 Skizofreniforeningen
 SLE/lupus – Diagnosenetværk, Gigtforeningen

DOMINICAN REPUBLIC

Asociación Mujeres Solidarias Inc. (AMSI)
 Fundación Un Amigo Como Tú
 Renacer – Fundación Dominicana de Esclerorisis Múltiple
 Sociedad Dominicana de Pacientes GIST

ECUADOR

APEMEDE – Asociación de Pacientes con Esclerosis Múltiple y Enfermedades Desmielinizantes Ecuador

EGYPT

Egyptian Association for Care of Heart Failure Patients (EACHFP)/الجمعية المصرية لرعاية مرضى قصور القلب

EL SALVADOR

ASAPRECAN – Asociación Salvadoreña para la Prevención del Cáncer

ETHIOPIA

Ethiopian Hemophilia Society (EHS)

FINLAND

Allergia-, Iho- ja Astmaliitto ry
 Kainuun neuroyhdistys ry
 Keski-Pohjanmaan Neuroyhdistys ry
 Propo Suomen eturauhassyöpäyhdistys ry
 Suomen Luustoliitto ry
 Suomen Nivelyhdistys ry

FRANCE

AAAVAM – Association Aide Aux Victimes des Accidents des Médicaments
 AFMT – Association Française des Malades de la Thyroïde
 AFPF – Association Fibroses Pulmonaires France
 Alliance du Cœur Sud-Ouest
 AMIS – Association des Myasthéniques Isolés et Solidaires

AMSAO – Association des Malades Souffrant d'Angio-oedème
 ASF – Association des Sclérodermiques de France
 ASPIC – Association pour les Patients Insuffisants Cardiaques et leurs proches
 Association des diabétiques du Finistère (AFD 29)
 Association Française pour la Recherche sur la Trisomie 21 (AFRT)
 Association France Spondyloarthrites (AFS)
 Association LIFE
 Atoutcancer
 Diab'Aide 67
 Fédération Nationale des Aphasiques de France (FNAF)
 FFGP – Fédération Française des Groupements de Parkinsoniens
 FGCP – Fédération France Greffe Cœur et/ou Poumons
 HPN France – Aplasie Médullaire
 Sol En Si
 UAFLMV – Union des Associations Françaises de Laryngectomisés et Mutilés de la Voix

GERMANY

BerLUN e.V.
 Deutsche Interessengemeinschaft Phenylketonurie (DIG PKU) und verwandte angeborene Stoffwechselstörungen e.V.
 Deutsches Expertennetzwerk HIV/Hepatitis e.V. (DCAB)
 Diabetes-Projekt The Gambia e.V.
 Friedreich Ataxie Förderverein e.V.
 Herzschäche Deutschland e.V.
 Lebertransplantierte Deutschland e.V.
 Leukämie und Lymphom SHG Ruhr Lippe e.V.
 MigräneLiga e.V. Deutschland
 Parkinson-Forum Kreis Steinfurt e.V.
 Pro Plus Nord e.V.
 pro plus rlp e.V.
 Selbsthilfe Landesverband für Osteoporose (LfO) Bayern
 Wendepunkt Schlaganfall

GREECE

AGORA (Federation of Associations for Patients with RMDs of Southern Europe)
 E.E.N.A.Λ. – Ελληνική εταιρία νόσου alzheimer και συναών Διαταραχών, νομού Λαρισας
 Ελληνική Ένωση για την Αντιμετώπιση της Σκλήρυνσης Κατά Πλάκας Δυτικής Ελλάδος (ΕΕΑΣΚΠ)

Ελληνικός Σύλλογος Πνευμονικής Ίνωσης
«Πνεύμονες Ζωής»

K3 – Κέντρο Καθοδήγησης Καρκινοπαθών
Πανελλήνιος Σύνδεσμος Πασχόντων από
Συγγενείς Καρδιοπάθειες

Πανηπειρωτική Ένωση για τον Νεανικό
Διαβήτη (Π.Ε.Ν.ΔΙ.)

Σύλλογος Ατόμων με Νεανικό Διαβήτη και
Κοιλιοκάκη Πρέβεζας

Σύλλογος Καρκινοπαθών Κ.Ε.Φ.Ι.

Σύλλογος Σκελετικής Υγείας Πεταλούδα

VHL Family Alliance Greece

GUATEMALA

ANGEL – Asociación Nacional
Guatemalteca para las enfermedades de
depósito lisosomal

HONDURAS

Sociedad Hondureña de Hemofilia

HONG KONG

癌症資訊網慈善基金

HUNGARY

Magyar Lupus Egyesület

Mályvavirág Alapítvány

PIBE – Primer Immunhiányos Betegek
Egyesülete

INDIA

ARDSI – Alzheimer's and Related Disorders
Society of India

ASWS – Ankylosing Spondylitis Welfare
Society

EMpower India

Hepatitis Foundation of Tripura (HFT)

Multiple Sclerosis Society of India (MSSI) –
Chennai Chapter

National Thalassaemia Welfare Society
(NTWS)

Organization for Rare Diseases India (ORDI)

IRAQ

الجمعية العراقية لمكافحة سرطان
الثدي للمساهمة الفعالة في
مكافحة سرطان الثدي

IRELAND

IMPERO – Irish Mental Patients' Educational
and Representative Organisation

ISRAEL

Enzyme – Association for patients with
Pompe disease

עמותת חן לפרייון ודיים

ITALY

A.I.L.S. – Associazione Italiana Lotta alla
Sclerodermia ODV

A.I.S.A. (Associazione Italiana per la lotta
alle Sindromi Atassiche) Lazio OdV

A.L.I.Ce. Italia Onlus

A.M.I.C.I. Lazio – Associazione Malattie
Infiammatorie Croniche dell'Intestino

A.M.A.R.E. Onlus

A.P.R.I. – Associazione Cimadori per la
Ricerca Italiana sulla Sindrome di Down,
l'Autismo e il Danno Cerebrale

A.T.E. – Associazione Toscana Emofilici OdV

AAPRA ODV-ETS – Associazione Ammalati
Pazienti Reumatici Autoimmuni

ADGT – Associazione Diabete Giovanile
della Provincia di Trento ODV

AICH Roma OdV – Associazione Italiana
Còrea di Huntington Roma Onlus

AIP LMC APS – Associazione Italiana
Pazienti Leucemia Mieloide Cronica

AMIP – Associazione Malati di Ipertensione
Polmonare ODV ets

ANED – Associazione Nazionale
Emodializzati Dialisi e Trapianto

ANED Puglia

ANIAD Abruzzo OdV

APIC – Associazione Pazienti Italiani di
Colangiocarcinoma

APMARR – Associazione Nazionale Persone
con Malattie Reumatologiche e Rare APS

Associazione Do.Ri.Ta

Associazione Contro il Melanoma OdV

Associazione Diabetici Vincenzo Castelli
della Provincia di Palermo

Cittadinanzattiva Campania APS

Cittadinanzattiva Regione Veneto APS

Comitato Macula

Europa Uomo Gruppo Bolzano

Europa Uomo Italia APS

FAND – Associazione Italiana Diabetici ODV

FEDIPSO – Federazione Italiana della
Psoriasi Onlus

LIFC Abruzzo – Lega Italiana Fibrosi Cistica
Abruzzo ODV

LIFC Lombardia – Lega Italiana Fibrosi
Cistica Lombardia ODV

Melanoma Day OdV

Nadir Onlus

Plus APS

JAPAN

(一社) 全国ファブリー病患者と家族の会
NPO法人キュアサルコマー

NPO法人筋強直性ジストロフィー患者会
(DM-family)

OCDお話し会

特定非営利活動法人膠原病・リウマチ・血管
炎サポートネットワーク

認定NPO 全国SCD・MSA友の会

骨髄増殖性腫瘍患者・家族会

KENYA

National Kidney Foundation of Kenya

KOREA

비영리 사단법인 간한우협회

사단법인 한국신장암환우회

한국암환자권익협의회

한국호흡기장애인협회

KOSOVO

Renesansa – Shoqata kundër kancerit të
gjirit

LATVIA

Biedrība „Saknes” – Ģenētiski pārmantoto
slimību pacientiem un līdzcilvēkiem

LITHUANIA

Bechterevo Liga Sergančiujų Draugija
„Judesys“

MALAYSIA

MRDSS – Malaysian Rare Disorders Society

MEXICO

AMECAT, A.C. – Asociación de Pacientes
Cáncer de Tiroides México

Asociación ALE, I.A.P.

Con Diabetes Si Se Puede, I. A. P.

Fundación de Alba, A.C.

Grupo Fabry de México, I.A.P.

IOF – International Osteoporosis Foundation

Organización Internacional de
Enfermedades de Baja Prevalencia

Unidos – Asociación Pro Trasplante de
Médula Ósea “Francisco Casares Cortina”,
A.C.

NEPAL

Blood Cancer Society Nepal

National Kidney Center (NKC) Nepal

NETHERLANDS

Alopecia Vereniging
 ALS patiëntenvereniging
 LMNA Cardiac Diseases Network
 Missie Tumor Onbekend
 MPN Stichting
 Sarcoidose.nl
 Stichting ANGOB – Algemene Nederlandse Geheel-Onthouders Bond
 Stichting Jij Speelt de hoofdrol
 Thyroid Federation International (TFI)
 Turner Contact Nederland
 Vereniging voor Anglo-oedeem
 WAPO – World Alliance of Pituitary Organizations

NEW ZEALAND

Bowel Cancer NZ
 Lung Foundation NZ
 New Zealand Pompe Network
 TSCNZ – Tuberous Sclerosis Complex New Zealand

NICARAGUA

ANEM – Asociación Nicaragüense de Esclerosis Múltiple

NIGERIA

Asthma Relief Campaign Project (ASMARCAP) Nigeria

NORWAY

Fabry Foreningen Norge
 LHL International
 Mental Helse
 Norges ME-forening – Vestland Fylkeslag
 Norsk Revmatikerforbund – diagnosegrupper Lupus Norge

PANAMA

APAD – Asociación Panameña de Asma y Deportes
 FeNAECCD – Federación Nacional de Asociaciones de Enfermedades Críticas, Crónicas y Degenerativas
 FUNARP- Fundación de Artritis Reumatoide de Panamá
 Fundación Panamá Respira
 Fundación Panameña de Hipertensión Pulmonar
 Fundación Psoriasis de Panamá

PHILIPPINES

ICanServe Foundation, Inc. – Breast Cancer Support Philippines
 Kidney Transplant Association of the Philippines, Inc. (KITAP)

POLAND

Fundacja Chorób Mózgu
 Fundacja Kapitan Światelko
 Instytut Praw Pacjenta i Edukacji Zdrowotnej (IPPEZ)
 Mazowieckie Stowarzyszenie Osób z Chorobą Parkinsona
 Ogólnokrajowe Stowarzyszenie Pomocy Chorym na Przewlekłą Białaczkę Szpikową (SPBS)
 Ogólnopolskie Stowarzyszenie Młodych z Zapalnymi Chorobami Tkanki Łącznej „3majmy się razem”
 Ogólnopolskie Stowarzyszenie Pacjentów ze Schorzeniami Serca i Naczyń „EcoSerce”
 Polskie Stowarzyszenie Choroby Huntingtona
 Polskie Stowarzyszenie Diabetyków, Oddział Świątokrzyski
 Stowarzyszenie Częstochowskie Amazonki
 Stowarzyszenie Neurofibromatozy Polska-Alba Julia
 Stowarzyszenie Wspierające Chorych na Chłoniaki „Sowie Oczy”

PORTUGAL

AADIC – Associação de Apoio aos Doentes com Insuficiência
 ACREDITAR – Associação de Pais e Amigos de Crianças com Cancro
 ADEXO – Associação Portuguesa de Pessoas que vivem com Obesidade
 AMPM – Associação de Mulheres com Patologia Mamária
 ANEM – Associação Nacional de Esclerose Múltipla
 APDPPróstata – Associação Portuguesa de Doentes da Próstata
 APFQ – Associação Portuguesa de Fibrose Quística
 APOFEN – Associação Portuguesa de Fenilcetonúria e Outras Doenças Metabólicas
 APOI – Associação Portuguesa de Osteógenese Imperfeita
 ASBIHP – Associação Spina Bífida e Hidrocefalia de Portugal
 ASPIC – Associação Portuguesa de Investigação em Cancro
 Associação Positivo – Grupos de Apoio e Autoajuda
 FamiliarMente – Federação Portuguesa das Associações das Famílias de Pessoas Com Experiência de Doença Mental
 OUVIR – Associação Portuguesa de Portadores de Próteses e Implantes Auditivos

RD-Portugal

SERaro.pt – Associação das Síndromes Excepcionalmente Raras de Portugal
 SPEM – Sociedade Portuguesa de Esclerose Múltipla
 UNITE Parliamentarians Network for Global Health
 VIDAs Associação Portuguesa de Menopausa

ROMANIA

ASMB – Asociația de Scleroză Multiplă București
 FABC – Federația Asociațiilor Bolnavilor de Cancer

SENEGAL

Association Taxawuma Assistance Handicap des Maladies Rares du Sénégal

SERBIA

Žuta mrlja – Udruženje pacijenata sa senilnom degeneracijom makule

SLOVENIA

Društvo distrofikov Slovenije
 Poglej! NGO
 Zveza društev Diabetikov Slovenije

SOUTH AFRICA

Rare Diseases South Africa (RDSA)
 South African Depression and Anxiety Group (SADAG)

SPAIN

ABHispalis – Asociación Bariátrica Híspalis Nacional
 ACCU Navarra – Asociación de Crohn y Colitis Ulcerosa de Navarra
 ACEADE – Asociación Córdobesa de Enfermos Afectados de Espondilitis
 ADC – Asociación Diabetis Catalunya
 ADEMTO – Asociación de Esclerosis Múltiple de Toledo y otras enfermedades neurológicas
 Adisen – Asociación Nacional de Addison y Otras Enfermedades Endocrinas
 AEFOP – Asociación Española de Fibrodisplasia Osificante Progresiva
 Alcer Granada
 Alcer Toledo
 ALERMA – Asociación de Enfermos Respiratorios de Málaga
 APACOR – Asociación de Pacientes Coronarios
 ASDIBO – Asociación de Diabéticos de Boadilla del Monte
 Asociación ASMD España

Asociación HIPOFAM – Asociación para la Información y la Investigación de la Hipomagnesemia Familiar
 Asociación Lupus Málaga y Autoinmunes
 Asociación Marco Luna
 Asociación T4 de lucha contra el Sida
 Asociación Valenciana de Trastorno Bipolar (AVTB)
 ASPACGRAP – Asociación de Pacientes Cardiacos de Granada y Provincia
 CESIDA – Coordinadora estatal de VIH y sida
 Comité Antisida Comunidad Valenciana está en Valencia
 EPOC España
 Esclerosis Múltiple León (EM León)
 EUPATI España
 FECMA – Federación Española de Cáncer de Mama
 Federación AICE – Federación de Asociaciones de Implantados Cocleares de España
 Federación Española del Síndrome de X Frágil (FESXF)
 FEFOC – Fundación Privada Jordi Estapé
 Foro Español de Pacientes (FEP)
 Grup SOM VIA
 Ictus Sevilla
 ONERO – Observatorio Nacional de Enfermedades Raras
 Reu+ – Comunidad de personas que conviven con enfermedades reumáticas
 Trabajando en Positivo

SWEDEN

Blodcancerförbundet
 Diabetesföreningen Västra Götaland
 Njurföreningen i Jämtland-Härjedalen
 Njurföreningen i Värmland
 Osteoporosföreningen i Östergötland
 Parkinsonföreningen Gävleborg
 Prostatacancerförbundet
 Prostatacancerföreningen T-Pro
 Prostatacancerföreningen Viktor
 Reumatikerdistriktet Älvsborg
 Reumatikerföreningen Enköping-Håbo
 Riksförbundet Cystisk Fibros (RiCF)
 Riksförbundet HjärtLung Helsingborg
 RLS-Förbundet
 Schizofreniförbundet
 Svenska FOP-föreningen
 Waldenströms Makroglobulinemi (WM) i Skandinavien

SWITZERLAND

Fabrysuise
 SPV – Schweizerische Polyarthritiker-Vereinigung
 SVAI – Schweizerische Vereinigung für Angeborene Immunodefekte

TAIWAN

台灣全癌症病友連線
 台灣關愛基金會
 社團法人中華民國乳癌病友協會
 社團法人中華民國血友病協會
 社團法人台灣基地協會
 財團法人台灣關愛基金會

THAILAND

Thailand Hepatitis Alliance มูลนิธิโรคตับ

TURKEY

Ankara Multipl Skleroz Derneği
 İbhayd Derneği
 Kanser Savaşçıları Derneği
 Kanserle Dans Derneği
 Parkinson Hasta ve Yakınları Derneği
 Sistinozis Hastaları Derneği
 Şizofreni Dernekleri Federasyonu
 TÜED – Türkiye Emekliler Derneği

UK

ALK Positive UK
 Anthonia Oyindamola Folakemi Afelumo Coshare (AOFAC) Foundation
 British Dupuytren's Society
 CRAF-UK – Cancer Research Advocates Forum
 GAIN – Guillain-Barré and Associated Inflammatory Neuropathies
 MPN Voice
 OPCSOG – Oxfordshire Prostate Cancer Support Group
 Pulmonary Fibrosis Trust (PF Trust)
 Stiff Person Syndrome Support Group and Charity
 Streetlight UK
 The Health Creation Alliance
 Working With Cancer
 Yorkshire Cancer Community

USA

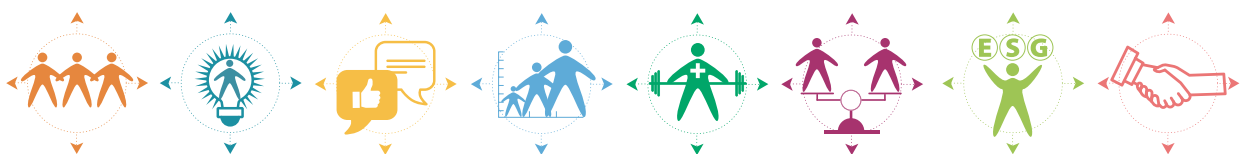
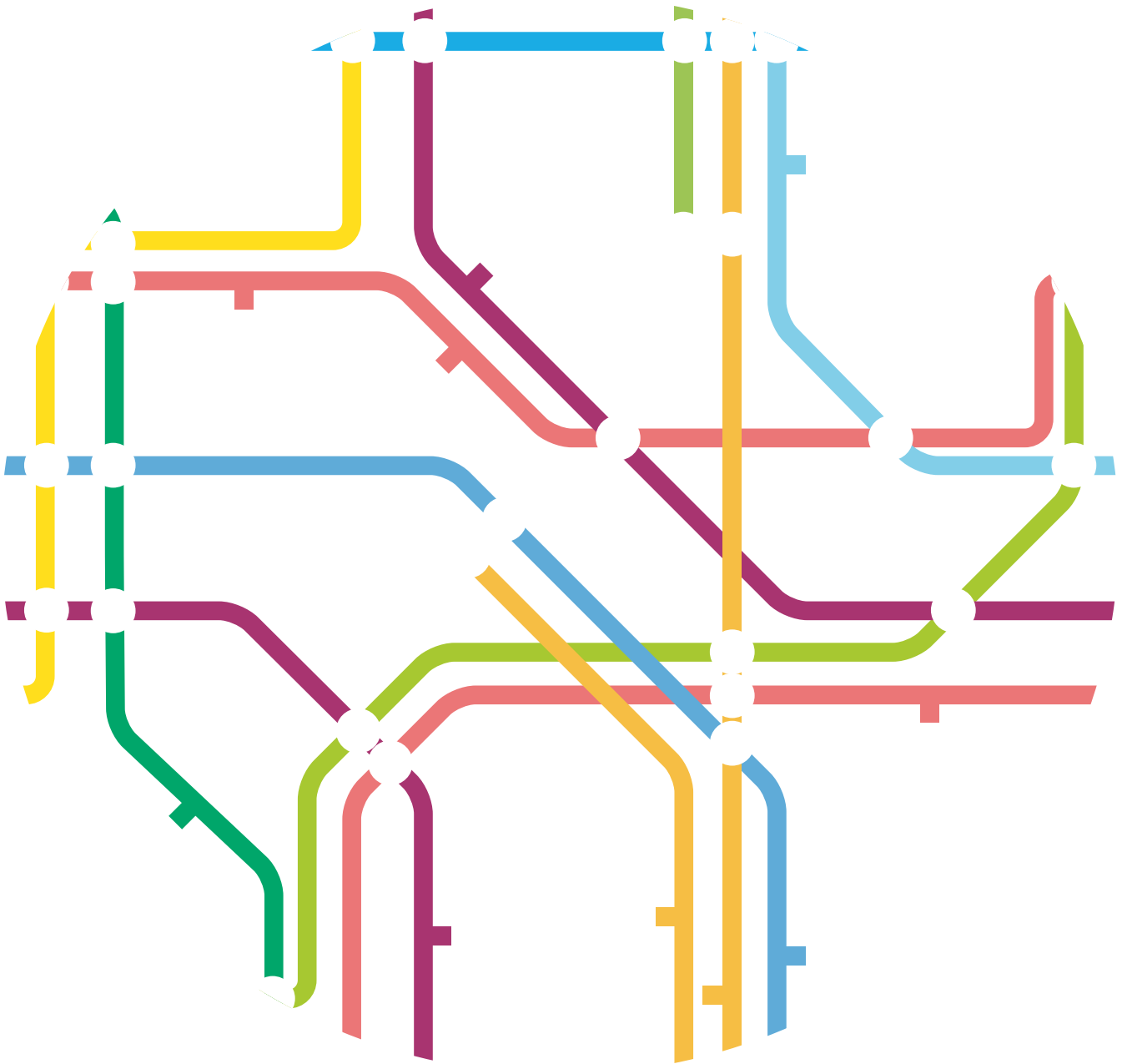
AnCan Foundation
 Arthritis National Research Foundation (ANRF)
 Cal Voices
 Children's Alopecia Project (CAP)
 Children's Tumor Foundation (CTF) and CTF Europe
 Chondrosarcoma CS Foundation
 Damien Ministries, Inc.
 Dementia Alliance International (DAI)
 First Descents
 Healthy Men Inc.
 Infusion Access Foundation (IAF)
 KidneyCancers.org
 Male Breast Cancer Global Alliance (MBCGA)
 Mental Health America of Kentucky (MHAky)
 Miles for Migraine
 More Than Lupus
 National Headache Foundation (NHF)
 One Cancer Place
 Pacific Northwest Bleeding Disorders (PNWBD)
 Sarasota Prostate Initiative
 Scleroderma Foundation of California
 Southeastern Diabetes Education Services (SDES)
 Susan G. Komen
 TED Community Organization
 The Gathering Place
 Utah NET Cancer Support Group
 Vitiligo Research Foundation (VR Foundation)

ZAMBIA

Kayala Childhood Cancer Foundation (KCCF)

ZIMBABWE

KidzCanZimbabwe
 Rare Diseases & Disabilities Africa (RaDDA) Foundation



Copyright© 2025 PatientView Ltd

ALL RIGHTS RESERVED

THIS BOOKLET IS THE PROPERTY OF
PATIENTVIEW, AND NO PART MAY BE
REPRODUCED WITHOUT PERMISSION, OR
PASSED ON TO ANY THIRD PARTY WITHOUT
THE PERMISSION OF PATIENTVIEW