



August 17, 2023

Payer Matrix

1400 N. Providence Road

Building 2, Suite 5000

Media, PA 19063

customerservice@payermatrix.com

Via Electronic Email

Re: Payer Matrix identifying itself as both a ‘Patient Advocacy Company’ and a ‘Leading Patient Advocate’ is untrue and misleading to consumers

Dear Payer Matrix Leadership:

The undersigned organizations are advocacy groups that represent patients across 34 organizations, representing 14 disease communities including Arthritis, Autoimmune disorder, Bleeding and Clotting disorders, Cancer, Cystic Fibrosis, Liver Disease, Lupus, Hepatitis, Hemophilia, HIV/AIDS, Neurological Conditions, Multiple Sclerosis, Psoriasis, Rare Disorders, and Spondylitis. We are writing to share our concerns regarding

Payer Matrix's recent self-classification as both a 'Patient Advocacy Company' as well as a 'Leading Patient Advocate.'¹

Patient advocacy groups are organizations that are developed to represent, support, and advocate on behalf of patients, caregivers, and families living with rare, chronic, complex, or specific conditions.² These organizations often retain 501(c)(3) or 501(c)(4) status designations as non-profit organizations. These organizations aim to advocate on behalf of their community to ensure *their voices, concerns, and stories*, are heard and responded to by actors within the health care system including, but not limited to, hospitals, health care providers, employers, health insurers, legislatures, and regulators. Patients, caregivers, and consumers rely on patient advocacy organizations to help them navigate the health care system and help ensure they can access their necessary care and treatments. Managing a chronic illness and receiving a new diagnosis can be very challenging experiences for individuals and their families, thus, patients need to have trusted organizations that they can turn to and rely on to act *in their best interest*.

Payer Matrix is not the type of organization described above; in fact, Payer Matrix profits each time it successfully enrolls a patient in a patient assistance program (PAP). As such, we believe it is highly inappropriate and misleading to consumers for Payer Matrix to classify itself as either a 'Patient Advocacy Company' or a 'Leading Patient Advocate.' Payer Matrix is a **for-profit** business representing the interest of employers and itself, not patients. Payer Matrix's business model requires unwitting patients to share personal information such as income, health status, and other personal data, so that Payer Matrix can enroll the patient in a PAP. Notably, these programs are already available to patients without Payer Matrix's participation. Payer Matrix's complex process often results in delaying patients' access to their treatments, forcing them to experience symptoms without relief, and disease progression. Moreover, unlike traditional patient advocacy organizations that are patient-centered to support patients' needs, preferences, and priorities, Payer Matrix mandates employees engage in this byzantine process or lose coverage for their medication, thereby requiring the patient to be responsible for the full cost of the drug. This demonstrates that Payer Matrix is a self-serving for-profit company, not a patient-centered advocacy organization representing the needs, preferences, and priorities of patients, caregivers, and families.

We strongly urge Payer Matrix to stop identifying as either a 'Patient Advocacy Company' or a 'Leading Patient Advocate' to ensure patients properly understand that Payer Matrix advocates for employer cost savings which lead to profits for Payer Matrix, not employees' health and access to treatments. Thank you for your consideration of our letter.

Please address any questions to Kim Czubaruk, Associate Vice President of Policy, CancerCare (kczubaruk@cancercare.org) and Kollet Koulianos, Senior Payer Provider Consultant, National Hemophilia Foundation (Kollet@3hbc.com).

Sincerely,

Aimed Alliance
Arthritis Foundation
Autoimmune Association
Bleeding Disorders Foundation of North Carolina
CancerCare
Colorectal Cancer Alliance
Community Liver Alliance

¹ Payer Matrix, *Leading Patient Advocate Slams AbbVie's Moves to Deny Vital Drugs to Needy Patients*, <https://www.kget.com/business/press-releases/cision/20230523PH07874/leading-patient-advocate-slams-abbvies-moves-to-deny-vital-drugs-to-needy-patients/>.

² Rare Beacon, *What Are Patient Advocacy Groups*, <https://www.rarebeacon.org/rare-diseases/why-patient-groups-matter/>.

Crohn's & Colitis Foundation
CSNK2a1 Foundation
Cystic Fibrosis Research Institute
Eastern Pennsylvania Bleeding Disorders Foundation
EveryLife Foundation for Rare Diseases
Foundation for Sarcoidosis Research (FSR)
Hemophilia Council of California
Hemophilia Federation of America
HIV+Hepatitis Policy Institute
Infusion Access Foundation
Juju and friends CLN2 Warrior Foundation
Little Hercules Foundation
Lupus and Allied Diseases Association, Inc.
Lupus Foundation of America
Multiple Sclerosis Association of America
National Consumers League
National Hemophilia Foundation
National Niemann-Pick Disease Foundation
National Psoriasis Foundation
Pacific Northwest Bleeding Disorders Foundation
Patient Access Network (PAN) Foundation
Spondylitis Association of America
STAC3.org
The AIDS Institute
The Akari Foundation
The Sumaira Foundation
Western Pennsylvania Bleeding Disorders Foundation