

## **Campaign to Protect Patient Privacy Rights** ~Consensus Principles~

We, the undersigned national, state, and local organizations, support maintaining the core protections of the federal substance use disorder patient confidentiality law (42 U.S.C. § 290dd-2) and regulations (42 CFR Part 2), referred to collectively as “Part 2,” to effectively protect the confidentiality of patients’ records, for the following reasons:

1. **The heightened privacy protections in 42 CFR Part 2 (“Part 2”) are as critical today** as they were when they were enacted more than 40 years ago, and must be preserved.<sup>i</sup>
2. **In the midst of the worst opioid epidemic in our nation’s history, we must do everything possible to increase – not decrease – the number of people who seek treatment.** The most recent national survey in 2015 found that an estimated 21.7 million people ages 12 or older (1 in 12 people) needed substance use disorder (“SUD”) treatment,<sup>ii</sup> but *only* 2.3 million of them received it in the past year.<sup>iii</sup> Our nation must do everything possible to increase the number of people entering treatment, not take actions such as eliminating confidentiality protections that will reduce the number of people willing to come forward for care.
3. **SUD is unique among medical conditions because of its criminal consequences and the rampant discrimination people face.** For most forms of SUD, the illness itself involves behavior that is criminalized. SUD patients are therefore vulnerable to arrest, prosecution, and incarceration, while patients with other chronic illnesses generally are not. Unlike individuals with any other illnesses or disabilities, many people with SUD are not protected by federal or state civil rights that protect people with disabilities from employment, housing and other types of discrimination.<sup>iv</sup> Unlike other types of health care information, disclosure of SUD patient records can not only discourage patients from seeking treatment, it subjects them to the risk of experiencing severe negative consequences and discrimination,<sup>v</sup> such as:
  - criminal investigation, arrest, and/or prosecution by law enforcement;
  - denials of disability, life, and other types of insurance;
  - loss of child custody; and
  - re-disclosures of SUD information that can cause loss of employment and other harm.
4. **With so much at stake, patients in SUD treatment should retain the right to consent when and to whom their records are disclosed.** Unlike HIPAA, consent should continue to be required for disclosures for treatment, payment, and health care operation purposes. Since some health care providers and payers continue to discriminate against patients living with substance use disorder, and HIPAA allows providers and payers to re-disclose records they receive to many others, patients should maintain the right to determine who can obtain their SUD information.

5. **Effective integration of SUD treatment with the rest of the health care system is critically important, and information exchange in accordance with confidentiality law and current technology is now possible.** To facilitate that process, SAMHSA recently amended the Part 2 regulations to further promote the integration of confidential SUD information into general health records. Now patients can easily share their SUD information with some or all of their treating providers (including non-SUD providers) with the patients' consent -- but without having to name every provider in the consent form -- in a variety of health care settings, health information exchanges, health homes, accountable care organizations, and coordinated care organizations.<sup>vi</sup> SAMHSA can also issue additional guidance if any unnecessary obstacles to communication between SUD and other health providers remain, but jettisoning all of Part 2's privacy protections -- including those unrelated to disclosures within the health care system -- would have devastating consequences for patients and the entire SUD treatment system.
- Software applications (e.g., "Consent2Share") allow patients to share their health data and permit the integration of existing electronic health record ("EHR") and health information exchange systems to support federal confidentiality requirements (including Part 2 and HIPAA). HIPAA requires that electronic health record systems comply not just with Part 2, but also with heightened state confidentiality protections governing mental health, HIV/AIDS, reproductive health, domestic violence and other sensitive health information.<sup>vii</sup> Hence, EHRs would need to have this functionality even if Part 2 did not exist.

**Part 2 provides safeguards for patients against disastrous results. HIPAA does not.** Unlike HIPAA, without patient consent, a special order, or other specific authorization, Part 2 prevents any covered health care provider who has patient-identifying SUD information, or anyone who receives it through patient consent or other Part 2 requirements, from disclosing this information to anyone else. Replacing Part 2's confidentiality requirements with HIPAA's looser standards would not sufficiently protect people seeking and receiving SUD treatment. Instead, many patients' lives would be severely harmed, and as a result, countless individuals needing SUD health treatment would be afraid to enter treatment.

**The federal SUD confidentiality rules must be maintained to protect patient privacy and to encourage those with opioid and other substance use disorders to enter treatment.**

CAMPAIGN TO PROTECT PATIENT PRIVACY RIGHTS:

A Future After Rehab ("AFAR") - Burlington and Central NJ

A New PATH - Spring Valley, CA

Health Privacy Principles

Addiction Haven – Chandler, AZ

Addiction Recovery Communities of California – Sacramento, CA

Addiction Recovery Environmental Homes (“A.R.E. Homes, LLC”) – Waukesha, WI

Addictions Resource Center, Waukesha, WI (ARC, Inc.)

Advocates for Recovery Colorado - Denver, CO

AIDS United

Alano Club of Portland

Alcohol & Addictions Resource Center, South Bend, IN

American Association for the Treatment of Opioid Dependence (AATOD)

American Group Psychotherapy Association

Apricity – Neenah, WI

Arthur Schut Consulting LLC

Association for the Advancement of Mexican Americans (AAMA) – Houston, Laredo, and San Antonio, TX

Association of Persons Affected by Addiction (APAA) – Dallas, TX

Atlantic Prevention Resources

Bangor Area Recovery Network, Inc. – Bangor, ME

California Consortium of Addiction Programs & Professionals (CCAPP)

Capital Area Project Vox–Lansing (MI)’s Voice of Recovery

Center for Recovery and Wellness Resources – Houston, TX

CFC Loud N Clear Foundation – Farmingdale, NJ

Chicago Recovering Communities Coalition

Colorado Behavioral Healthcare Council

Communities for Recovery – Austin, TX

Community Catalyst

Connecticut Community for Addiction Recovery (CCAR) - Hartford, CT

Council on Addiction Recovery Services (CAREs)-Orlean, NY

DarJune Recovery Support Services & Café – Green Bay, WI

Davis Direction Foundation - The Zone

Daystar Center

D.C. Recovery Community Alliance

Delphi Behavioral Health Group–Maryland House Detox

Detroit Recovery Project, Inc. – Detroit, MI

The DOOR-DeKalb Open Opportunity for Recovery

Drug and Alcohol Service Providers Organization of Pennsylvania

El Paso Alliance – El Paso, TX

Faces & Voices of Recovery

Faces and Voices of Recovery (FAVOR)-Grand Strand-SC

Faces and Voices of Recovery (FAVOR)-Greenville, SC

Faces and Voices of Recovery (FAVOR)-Low Country: Charleston, SC

Faces and Voices of Recovery (FAVOR)-Midlands: Columbia, SC

Faces and Voices of Recovery (FAVOR)-Mississippi Recovery Advocacy Project: Jackson, MS

Faces and Voices of Recovery (FAVOR)-Pee Dee: Florence, SC

Faces and Voices of Recovery (FAVOR)-Tri-County: Rock Hill, SC

Facing Addiction

Fellowship Foundation Recovery Community Organization - Margate, FL

Floridians for Recovery

Foundation for Recovery – Las Vegas, NV

Friends of Recovery-New York – Albany, NY

George B. Crane Memorial Center – Pittsfield, MA

Georgia Council on Substance Abuse – Atlanta, GA

Great Bear Recovery Collective – Juneau, AK

Greater Macomb Project Vox – Fraser, MI

Hansen Recovery Resource Center – Ventnor, NJ

Harm Reduction Coalition

Home of New Vision

HOPE for New Hampshire Recovery – Concord, NH

Indiana Addictions Issues Coalition – Indianapolis, IN

Jackson Area Recovery Community-Jackson, MI

Latah Recovery Center

Legal Action Center

Lifehouse Recovery Connection – San Diego, CA

Living Proof Recovery - Rome, GA

Long Island Recovery Association (LIRA) – Hauppauge, NY

Lost Dreams Awaken Center, Inc. – New Kensington, PA

Lotus Peer Recovery/Soberkerrville – Kerrville, TX

Maine Alliance for Addiction Recovery – August, ME

Massachusetts Organization for Addiction Recovery

Message Carriers of Pennsylvania, Inc. – Pittsburgh, PA

Mid-Michigan Recovery Services (NCADD Mid-Michigan Affiliate)

Minnesota Alternatives – Spring Lake Park, MN

Minnesota Recovery Connection – Minneapolis/St. Paul, MN

Missouri Recovery Network – Jefferson City, MO

NAADAC, the Association for Addiction Professionals

National Advocates for Pregnant Women

National Alliance for Medication Assisted Recovery (NAMA Recovery)

National Association for Children of Addiction (NACoA)

National Association of County Behavioral Health and Developmental Disability Directors (NACBHDD)

National Association for Rural Mental Health (NARMH)

National Center on Domestic Violence, Trauma & Mental Health

National Council on Alcoholism and Drug Dependence, Inc. (NCADD)

National Council on Alcoholism and Drug Dependence-Central Mississippi Area, Inc.

National Council on Alcoholism and Drug Dependence-Maryland

National Council on Alcoholism and Drug Dependence-Phoenix

National Council on Alcoholism and Drug Dependence-San Fernando Valley

Navigate Recovery Gwinnett – Gwinnett County, GA

Navigating Recovery of the Lakes Region – Laconia, NH

New Jersey Association of Mental Health and Addiction Agencies

Northern Ohio Recovery Association (NORA) – Cleveland, OH

Oklahoma Citizen Advocates for Recovery and Transformation Association (OCARTA) - Oklahoma City, OK

Overcoming Addiction Radio, Inc.

Health Privacy Principles

Parent/Professional Advocacy League

Peer Coach Academy Colorado

Peer360 Recovery Alliance – Midland, MI

Pennsylvania Recovery Organizations-Alliance (PRO-A)

People Advocating Recovery (PAR) – Louisville, KY

People Living in Recovery (PLR) – Rome, GA

Pennsylvania Recovery Organization–Achieving Community Together (PRO-ACT) – Warwick, PA

Portland Recovery Community Center – Portland, ME

Public Justice Center

REAL-Michigan (Recovery, Education, Advocacy & Leadership)

Reality Check, Inc. – Jaffrey, NH

Recover Project – Greenfield, MA

Recover Project/Western MA Training

Recover Wyoming – Cheyenne, WY

RecoveryATX – Austin, TX

Recovery Alliance of Austin

Recovery Allies of West Michigan – Grand Rapids, MI

Recovery Café- Seattle, WA

Recovery Communities of North Carolina – Raleigh, NC

Recovery Community of Durham – Durham, NC

Recovery Consultants of Atlanta

Recovery Epicenter Foundation, Inc. – St. Petersburg, FL

Recovery Force of Atlantic County – Brigantine, NJ

Recovery-Friendly Taos County – Taos, NM

Recovery is Happening – Rochester, MN

Recovery Resource Council

Recovery Organization of Support Specialist

Revive Recovery, Inc.

Rhode Island Cares About Recovery (RICARES)

Rhode Island Communities for Addiction Recovery Efforts (RICARES) – Warwick, RI

Health Privacy Principles

Rochester Community Recovery Center

ROCovery Fitness – Rochester, NY

SAARA of Virginia

Safe Harbor Recovery Center

Solano Recovery Project – Fairfield, CA

Solutions Recovery, Inc. - Osh Kosh, WI

SMART Recovery (Self-Management and Recovery Training)

S.O.S. Recovery Community Organization – Dover & Rochester, NH

SpiritWorks Foundation – Williamsburg, VA

Springs Recovery Connection – Colorado Springs, CO

Tennessee Association of Alcohol, Drug & other Addiction Services (TAADAS)

The Ammon Foundation

The Bridge Foundation

The Courage Center – Lexington, SC

The Door-DeKalb Open Opportunity for Recovery – Decatur, GA

The Ladders Recovery Community – City of Oconomowoc, WI

The McShin Foundation – Richmond, VA

The Ohana Center for Recovery

The Phoenix

The RASE Project – Central Florida

The Recovery Channel

The Serenity House of Flint – Flint, MI

There Is No Hero in Heroin – Las Vegas, NV

Tia Hart Community Recovery Program – Raeford, NC

Together Our Recovery Center Heals (T.O.R.C.H.), Inc. – Lewiston, MT

Treatment Communities of America

Treatment Trends, Inc.

Trilogy Recovery Community – Walla Walla, WA

U MARC (United Mental Health and Addictions Recovery Coalition) – Chicago, IL

Utah Support Advocates for Recovery Awareness (USARA) – Salt Lake City, UT

Vermont Recovery Network – Montpelier, VT

Voices of Hope for Cecil County, MD

Voices of Hope Lexington - KY

Voices of Recovery San Mateo County, CA

WAI-IAM, Inc. and RISE Recovery Community – Lansing, MI

Washtenaw Recovery Advocacy Project (WRAP) – Ann Arbor, MI

Wisconsin Recovery Community Organization (WIRCO) – Sheboygan, WI

Wisconsin Voices for Recovery – Madison, WI

Young People in Recovery

---

<sup>i</sup> See amended federal code sections 21 U.S.C. §1175 (drug abuse, 1972 & 1974); 42 U.S.C. §4582 (alcohol abuse, 1974) and the federal confidentiality rules passed to implement the changes at 42 CFR Part 2 (published at 40 Fed. Reg. 27802, (July 1, 1975); effective on Aug. 1, 1975).

<sup>ii</sup> U.S. Dep’t of Health & Human Services, Substance Abuse & Mental Health Services Admin., *Key Substance Use and Mental Health Indicators in the United States: Results from the 2015 National Survey on Drug Use and Health 25* (Sept. 2016), available at <https://www.samhsa.gov/data/sites/default/files/NSDUH-FFR1-2015/NSDUH-FFR1-2015/NSDUH-FFR1-2015.pdf>.

<sup>iii</sup> *Id.* at 26-27.

<sup>iv</sup> For example, the Americans with Disabilities Act, Fair Housing Act and other laws explicitly exclude people engaged in “current illegal drug use.” This means that people addicted to opioids or illegal drugs, or misusing prescription medications, who come forward for treatment would have no protection from losing their jobs if, for example, their treatment records were disclosed by a payer to their employer.

<sup>v</sup> See generally Legal Action Center, *Discrimination Against Patients With Substance Use Disorders Remains Prevalent and Harmful: The Case for 42 CFR Part 2* (Apr. 13, 2017), available at <http://healthaffairs.org/blog/2017/04/13/discrimination-against-patients-with-substance-use-disorders-remains-prevalent-and-harmful-the-case-for-42-cfr-part-2/>.

<sup>vi</sup> 42 CFR § 2.31.

<sup>vii</sup> FEi Systems, *Consent2Share*, available at <http://www.feisystems.com/what-we-do/health-it-application-development/consent2share/>. See also Prince George’s County, Maryland, *Consent2Share*, available at <http://www.princegeorgescountymd.gov/1709/Consent2Share>.