

# Colorado Consortium for Prescription Drug Abuse Prevention

## Affected Families & Friends Work Group Meeting Minutes

October 18, 2024 via Zoom

### **Present:**

Sarah Werner and Tracy Ritter, Co-chairs  
Waltrina DeFrantz-Dufour, University of Denver  
Lorraine Hoover, The Raymond Rountree, Jr. Foundation  
Julie Wright, Maddie Wright Foundation  
D.E. Foster, Benzodiazepine Action Work Group  
Consortium: Hilary Bryant, Jen Place, Rosemarie MacDowell

**Absent:** See attached roster.

Work group Co-chair Sarah Werner called the meeting to order at 12:05 p.m.

### **Approval of Minutes:**

A motion was made to approve the September meeting minutes. Motion approved.

### **Presentation: Benzodiazepines: what they are and why are they a problem (D.E. Foster):**

D.E. Foster founded the support sites *Easing Anxiety* and *Uneven*. He is host of the *Benzo Free* and *Uneven* podcasts and authored the book *Benzo Free: The World of Anti-anxiety Drugs and the Reality of Withdrawal*. He is also co-founder and former Co-chair of the Consortium Benzodiazepine Action Work Group. He has written and co-authored a number of journal articles, including the study identifying benzodiazepine-induced neurological dysfunction (BIND), drawing on lived experience. A copy of the presentation is attached to the minutes and includes information on support groups and helpful websites. Presentation summary:

D has lived experience, having been prescribed 1 to 2 milligrams daily of the potent drug Klonopin by his physician for 12 years. D was never given any warning about the drug's side effects and experienced significant withdrawal symptoms when he began to taper the drug. The symptoms resulted in D being bedridden at times, which also affected his career. D has been benzodiazepine free for 10 years, but has still experienced setbacks as recent as this past year.

The vast majority of people D works with have taken benzodiazepines as prescribed. In 2020, the FDA issued a black box warning pertaining to the long-term use of benzodiazepines and withdrawal issues. D reviewed dose tolerance and withdrawal symptoms as well as the names of available benzodiazepines (Ativan, Valium, Librium, among others). Another group of drugs called Z drugs (non-benzodiazepine drugs such as Sonata, Ambien, and Lunesta) seem to have similar complications.

In 2023 D, along with Christy Huff, MD, Alexis Ritvo, MD, and others, authored a paper on Benzodiazepine-Induced Neurological Dysfunction (BIND) and presented the survey findings to the 2024 American Society of Addiction Medicine (ASAM) Rx Summit. The paper was featured in *PLOS ONE* as well as *Psychology Today* and *USA Today*. BIND is defined as a constellation of functionally limiting physical and psychological neurological symptoms that can persist from weeks to years after discontinuation of benzodiazepines.

D summarized the role and difficulties experienced by caregivers of individuals dealing with benzodiazepines and withdrawal and the importance of having a support system. He also addressed the hostility and lack of knowledge demonstrated by many physicians regarding benzodiazepine prescribing, withdrawal, and treatment and the importance of finding a physician willing to work with patients having difficulties with tapering. D mentioned Dr. Josef Witt-Doering's clinic for tapering of SSRIs, benzodiazepines, and other drugs.

<https://taperclinic.com/dr-josef-witt-doerring/>

Work group members briefly discussed the recent death of Dr. Christy Huff, Benzodiazepine Action Work Group member. Members also discussed reports of students using ketamine for therapeutic purposes and how all drugs have side effects.

For additional information or to obtain the presentation slides in PowerPoint format, email:

[foster@uneven.life](mailto:foster@uneven.life)

### **Announcements:**

"Stories in Black and White: Sharing the Impact of the Overdose Epidemic", a photography exhibit aiming to reduce the stigma of substance use disorder (SUD) by highlighting the stories of those in recovery and honoring those who lost their life to an overdose, was presented during the Attorney General's Opioid Abatement Conference on September 30th and during the Rethinking Recovery Conference on October 1st in Loveland. The work group plans to continue to work with the CDC Foundation and the RMHIDTA to assist in the creation of similar exhibitions in communities throughout Colorado.

Compassion Cards Project: Compassion cards express the work group's concern for families affected by substance use disorder. The cards include a QR code and a link to the work group's Resource Guide. Cards have been printed and delivered to the Denver Medical Examiner's Office for distribution to families suffering the loss of a loved one. Additional cards will be shared with advocacy and support groups.

Colorado Families and their Role in Combatting the Opioid Crisis - a Family Organization Roundtable October 24, 2 - 4p.m. via Zoom. 10 family-founded organizations, 13 individuals, and 4 consulting/development organizations will be attending. The purpose of the roundtable is to enhance awareness and foster communication and cooperation. Work group members were asked to contact the co-chairs directly with suggestions for any additional organizations that may be interested. The Steadman Group will be speaking about the business aspects of forming a family foundation.

### **Future Meeting Topics:**

The work group is currently planning 2025 meeting topics. Suggested topics can be shared during future work group meetings.

### **Adjourn/next meeting date:**

The meeting adjourned at 1 p.m. The next meeting will be held on Friday, November 15, 2024 from 12 to 1 p.m. Meeting presentation: *Family Support in Recovery*, Jessica Triplett. The work group will not meet in December.

Attachments: Work group roster, presentation slides