



Developing a Sustainable Consumer Clearinghouse for Translational Depression and Bipolar Disorder Research



Project Aims

WHAT CONSUMERS SAY ABOUT PARTICIPATING IN DEPRESSION-BIPOLAR RESEARCH

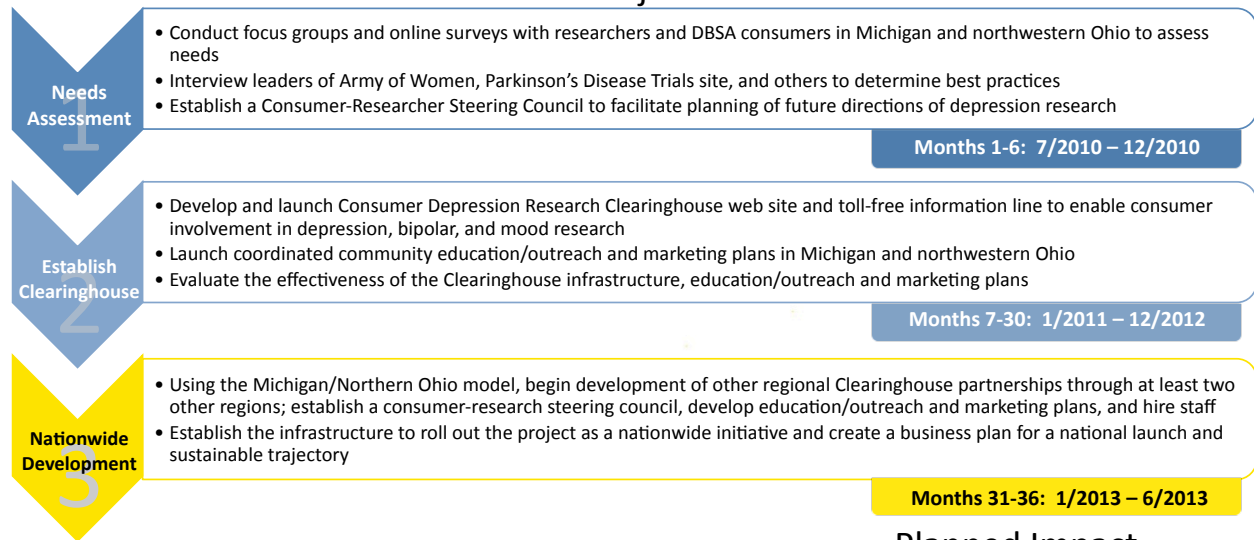
Sources: *Consumer focus groups, November 2010 – January 2011; DBSA Web Survey of Consumer Attitudes Toward Clinical Research, Spring 2010*

- We don't know enough about the broad range of research taking place, and that it's not only drug research.
- We can't easily find information on research participation opportunities.
- We don't trust researchers to act in our best interests, especially in research funded by pharmaceutical companies.
- We don't want to risk relapse by trying new drug treatments.
- Researchers need to understand what motivates us to participate in research and provide appropriate positive reinforcement.
- It's important for us to feel like a valued part of the research team and to be treated with respect.
- Once research is completed, we want to hear about the results.
- We don't know about and understand research safety protections.
- Many of us are willing to participate in research requiring medical tests, to make information available from our medical records, and to provide tissue or gene samples.
- We're more likely to participate in research that:
 - Explores a new talk therapy (vs. a new medication)
 - Is run or endorsed by our clinical providers

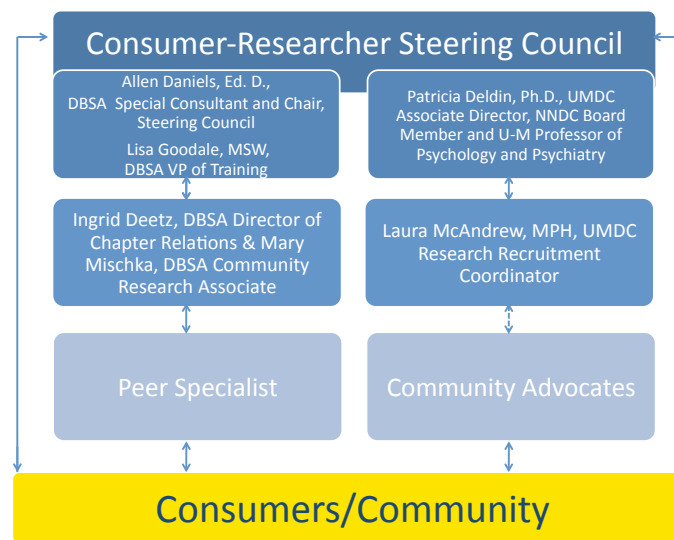
To address these and other issues, the Depression and Bipolar Support Alliance (DBSA) and the University of Michigan Comprehensive Depression Center are developing a comprehensive strategy to increase consumer research participation thereby facilitating the identification, treatment and prevention of mood disorders by:

- (1) Linking consumers interested in participating in depression research with scientists
- (2) Providing consumers the opportunity to have a voice in the priorities, direction and evaluation of this research.

Social networking strategies, community engagement and personalized outreach will be employed to achieve these aims. The program is being launched regionally in Michigan and northern Ohio, then evaluated for effectiveness and made sustainable through expansion to National Network of Depression Centers (NNDC) member sites and other mental health organizations.



Administrative Structure & Key Personnel



Planned Impact

- Aim 1** - Create opportunities to **voice needs and concerns** about research recruitment through consumer-researcher Steering Council and focus groups
- Aim 2** - **Increase knowledge of best practices** in consumer research recruitment from interviews
- Aim 3** - **Increase understanding** of best practices for recruitment from evaluation of education and outreach efforts in Michigan/Northern Ohio region
- Aim 3** - **Increase and sustain volunteer enrollment in research studies** at NNDC member institutions

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