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

Project Aims

- Conduct focus groups and online surveys with researchers and DBSA consumers in Michigan and northwestern Ohio to assess needs
- Interview leaders of Army of Women, Parkinson’s Disease Trials site, and others to determine best practices
- Establish a Consumer-Researcher Steering Council to facilitate planning of future directions of depression research

- Develop and launch Consumer Depression Research Clearinghouse web site and toll-free information line to enable consumer involvement in depression, bipolar, and mood research
- Launch coordinated community education/outreach and marketing plans in Michigan and northwestern Ohio
- Evaluate the effectiveness of the Clearinghouse infrastructure, education/outreach and marketing plans

- Using the Michigan/Northern Ohio model, begin development of other regional Clearinghouse partnerships through at least two other regions; establish a consumer-research steering council, develop education/outreach and marketing plans, and hire staff
- Establish the infrastructure to roll out the project as a nationwide initiative and create a business plan for a national launch and sustainable trajectory

Planned Impact

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

Administrative Structure & Key Personnel

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<tr>
<th>Consumer-Researcher Steering Council</th>
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<tr>
<td>Patricia Deldin, Ph.D., UMDC Associate Director, NNDC Board Member and U-M Professor of Psychology and Psychiatry</td>
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<tr>
<td>Ingrid Deetz, DBSA Director of Chapter Relations &amp; Mary Mischko, DBSA Community Research Associate</td>
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<td>Laura McAndrew, MPH, UMDC Research Recruitment Coordinator</td>
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| Peer Specialist |
| Community Advocates |

**Contact Information**

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**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.

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