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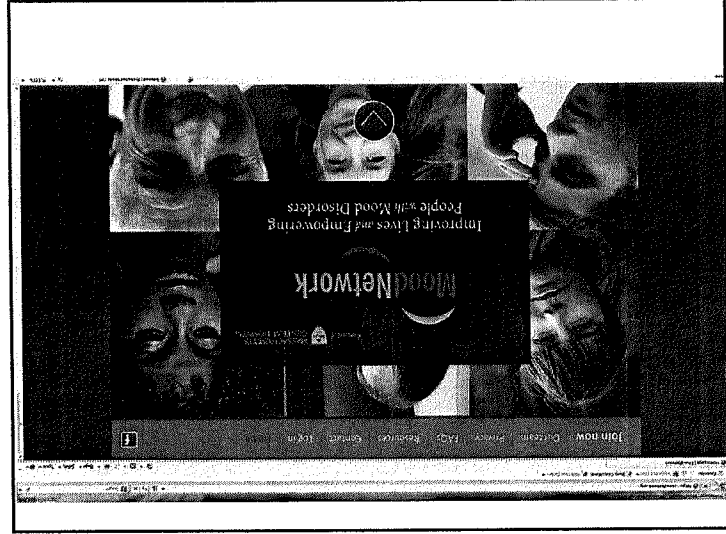
**Andrew A. Nierenberg, MD Disclosure Statement**

Other Income	MBL Publishing for past services as Editor-in-chief of CNS Spectrums; Slack Inc. for services as Associate Editor of Psychiatric Annals; Editorial Board, Mind Mood Memory, Behavior Publications
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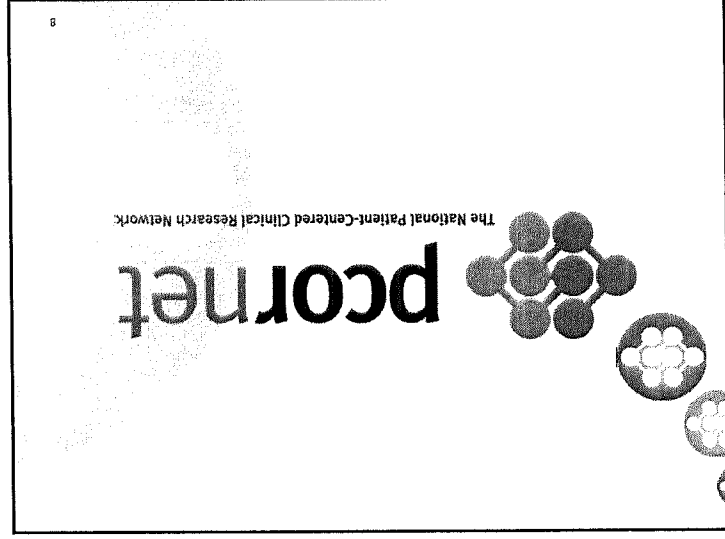
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Honoraria From	MGH Psychiatry Academy in the past 3 years (Prior to 3 years ago, honoraria from Bristol-Myers Squibb, Cyberonics, Forest Pharmaceuticals, GlaxoSmithKline, Eli Lilly, Shire, Wyeth-Ayerst), No speaker bureaus since 2003

**Patient Powered Research Network**



On-line community of experts with  
 experience collaborating with  
 researchers and clinicians to  
 improve lives.

Infrastructure for research.



## PCORnet Goals

- **Improve**
  - nation’s capacity to conduct comparative effectiveness research
- **Create**
  - large, highly representative, national patient-centered clinical research network
- **Conduct**
  - clinical outcomes research
  - comparative effectiveness research

## Patient Powered Research Networks

- **Stakeholders at the center**
  - patients, advocacy groups, physician organizations, academic centers, others.
- **Patient engagement key**
- **Broad range of conditions and diseases**
- **Variety in populations represented (including pediatrics, underserved populations etc.)**
- **50% rare diseases**
- **Several have capacity to work with biospecimens**



- **Network of 29 networks**
  - **Clinical Data Research Networks (CDRNs)**
    - 11 large conglomerations of health care systems
  - **Patient Powered Research Networks (PPRNs)**
    - 18 consortiums of people with related conditions
    - 9 rare diseases, 9 common diseases
- **Common data model**
- **Minimum of 20 million people**

**Experts with experience of depression or bipolar disorder at the center.**

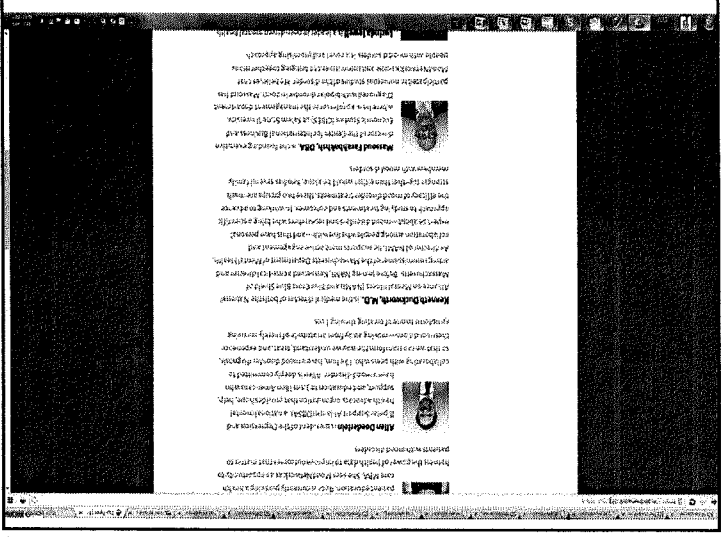
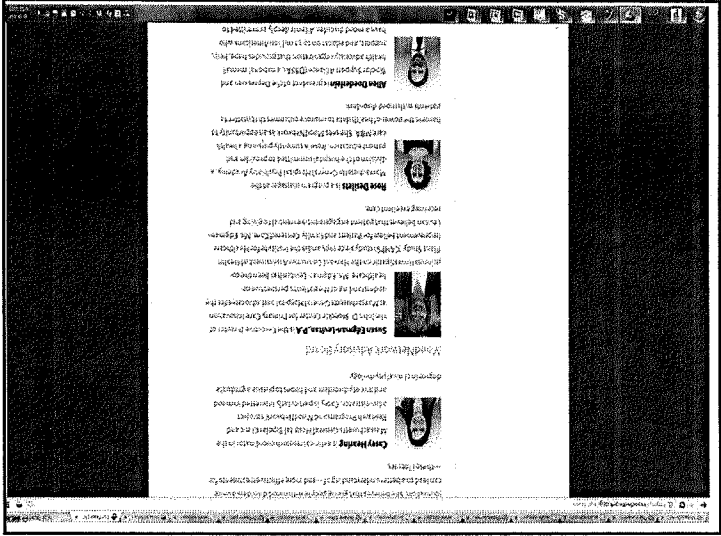
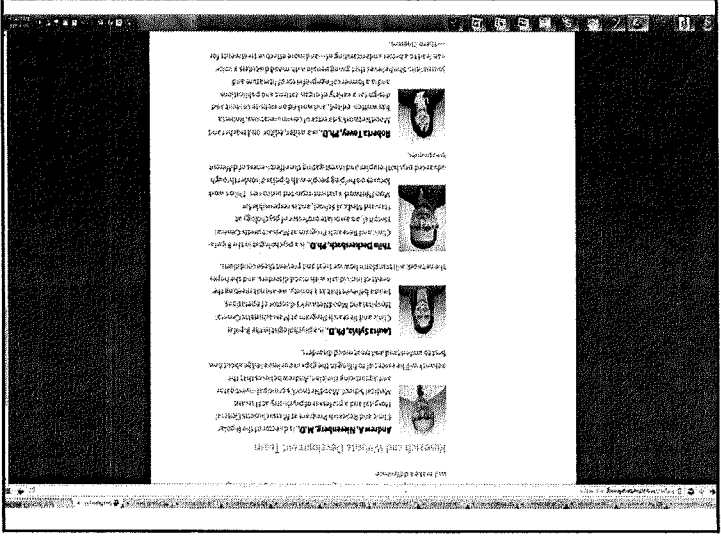
Every level of governance.  
Shared decision making.  
Co-production.  
Co-learning.

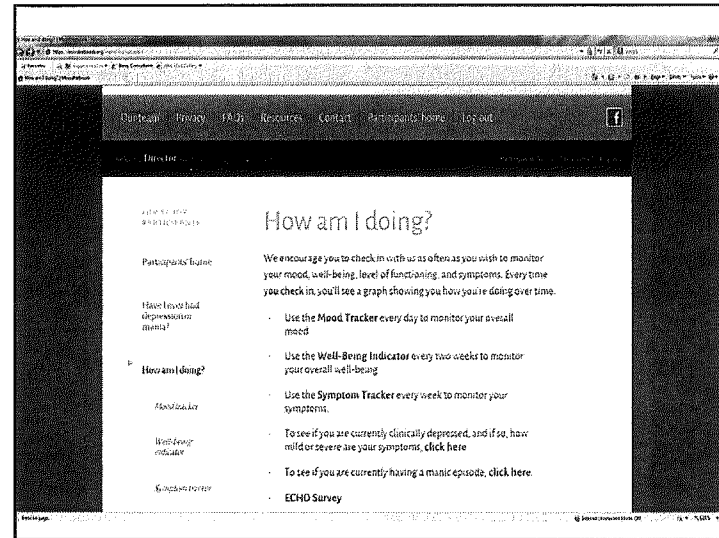
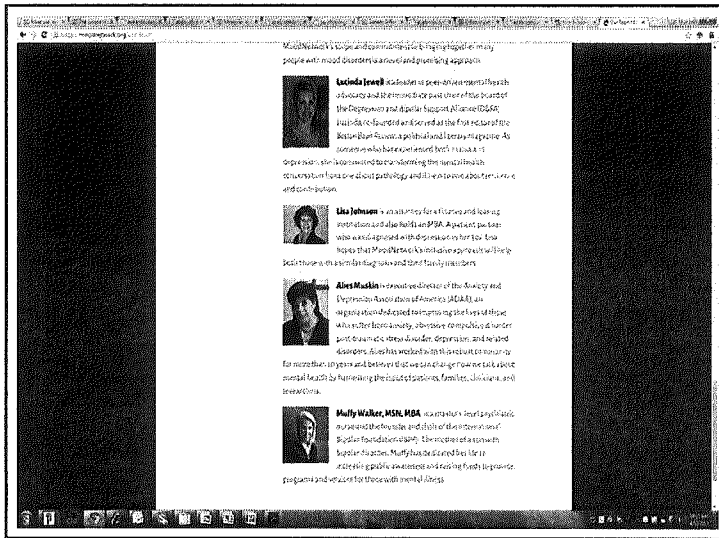


MoodNetwork

**Advocacy groups**

- DBSA - Allen Doederlein
- IBF - Muffy Walker
- ADAA - Alise Muskin
- NAMI - Ken Duckworth, MD
- National Association of Colored People Against Suicide - Donna Holland Barnes, PhD





### Value Proposition for Participants

- Diagnostic tools
- Symptom tools
- Wellness measures
- Experience of care
- Research priorities
- Forums
- Blogs

### Opportunities to participate in research.

**Enrollment statistics (as of 8/7/15)**

Age Category	%
18 through 44	58.8
45 through 64	37.4
65 plus	3.8
Sex	Total
Male	18.2
Female	78.8
Ambiguous	0.2
Other	0.8
Unknown	2.0

**Current enrollment started 5/28/15**

- Participants 1,375
- Unique visitors 9,049
- Visits 14,452
- Page views 83,086

**Enrollment statistics (as of 8/7/15)**

Depression	Total
Yes	95.3%
No	4.7%
Hypomania or Mania	Total
Yes	81.6%
No	18.4%

**Enrollment statistics (as of 8/7/15)**

Hispanic or Latino	%
Yes	7.8
No	83.9
Unknown	8.3

**Enrollment statistics (as of 8/7/15)**

Race/Ethnicity	%
Percent White	84.9
Percent American Indian/Alaska Native	0.8
Percent Asian	4.0
Percent black or African American	2.0
Percent Unknown	3.1
Percent Other	0.0
Percent Multiple Race	5.2

**Enrollment statistics (as of 8/7/15)**

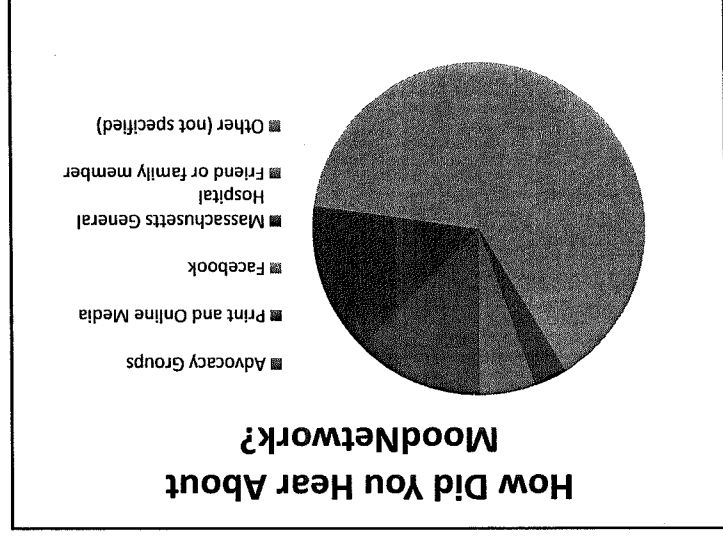
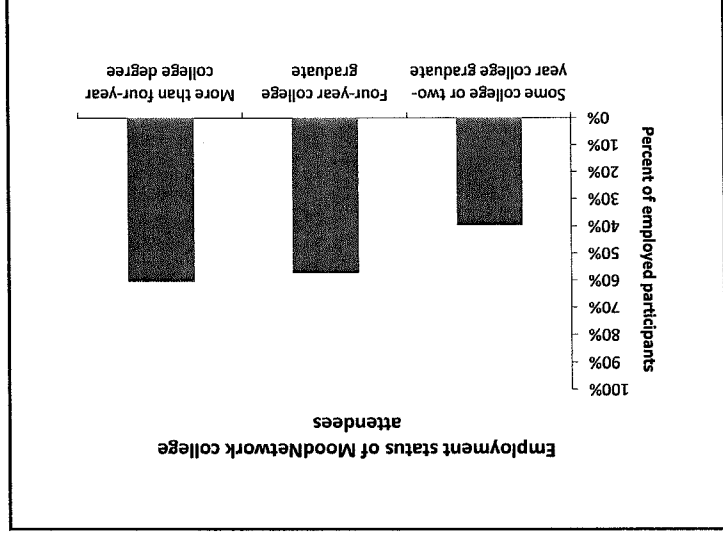
Marital Status	Total
Now married	35.9%
Living with a partner/significant other	11.4%
Widowed	1.7%
Divorced	16.4%
Separated	5.1%
Never married	25.5%
Unknown	3.9%

**Enrollment statistics (as of 8/7/15)**

Education	Total
Some high school but did not graduate	3.3%
High school graduate or GED	11.7%
Some college or two-year degree	34.8%
Four-year college graduate	22.9%
More than four-year college degree	23.8%
Unknown	3.1%

**Enrollment statistics (as of 8/7/15)**

Employment	Total
Employed	615
Unemployed	287
Retired	124
Student	161
Homemaker	148
Volunteer	135
Disabled	325

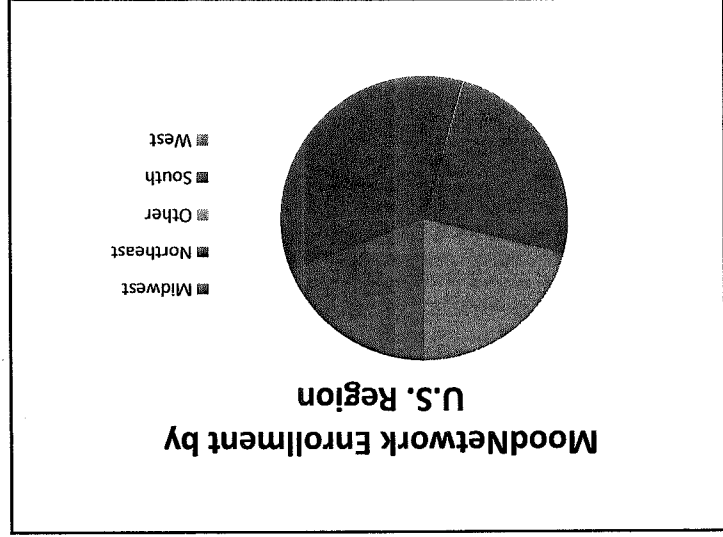


### Website Analytics (as of 8/7/15)

Device Used to Access MoodNetwork	Average Session Length	Average pages viewed per session	Total Users
Mobile Device	3:37	3.59	55.8%
Desktop Computer	6:13	5.28	32.0%
Tablet	3:57	3.50	12.2%

User Type	Percentage
Total	
Returning Visitors	35.1%
New Visitors	64.9%

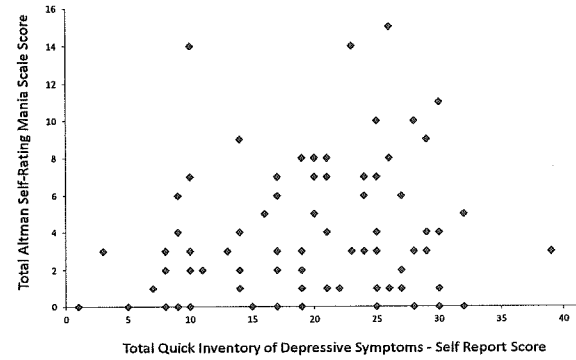




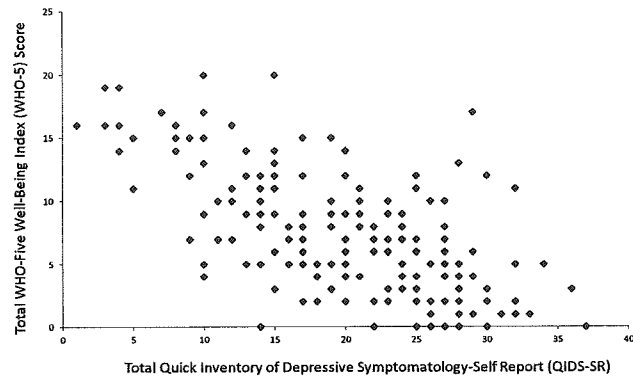
## Surveys

MINI International Neuropsychiatric Interview 6.0 - Depression
Composite International Diagnostic Interview - Mania
Quick Inventory of Depressive Symptomatology Self-Report
Altman Self-Rating Mania Scale
Patient Centered Outcomes Research Institute Symptom Tracker
WHO-5 Well-Being Index
Depression and Bipolar Support Alliance Wellness Tracker

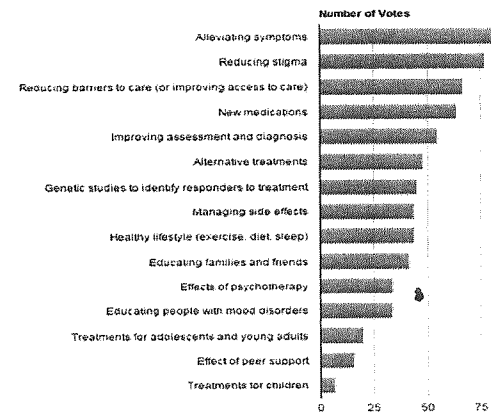
## Mania and depression severity in the MoodNetwork population



## Well-Being and depression severity in the MoodNetwork population



## Participant Research Priorities



### MoodNetwork Summary

- Unique governance with collaboration
- Experts with experience
  - Donate data
  - Prioritize research
  - Participate research
- Research infrastructure for the field

### NIMH SBIR Phase II Award

- Cogito, Inc.
  - App
  - Passive monitoring
  - GPS, accelerometer
  - Phone use
  - Surveys
  - Audio diary

### Forum Quotes (cont.)

- "I was diagnosed with bipolar disorder back in 1999. It has been a rough journey thus far. I believe I am resistant to meds for this horrible condition. I am hoping that being a part of this study will help advance medical treatments for this illness."

### Forum Quotes

- "I am so grateful to every person doing this research!!! You are an answered prayer!!! I am wishing, with the greatest of hope, that you will finally find a way to help people like me. What a Godsend that would be!! Thank you!!!"