8:15 a.m. Welcome and Opening Remarks
Mary Jane England, Committee Chair

8:30 – 9:00 Public Testimony
Moderator: Mary Jane England
- Brandy Parker
- Ilene Miller, Hope for Hypothalamic Hamartomas
- Carmita Vaughan, CURE
- Steve Wulchin
- Cheryl-Ann Tubby, American Epilepsy Society
- Mark Brooks, Abilities Network/Epilepsy Support Group
- Mylissa Daniels
- Kevin Malone, Epilepsy Therapy Project
- Melinda Heine

9:00 – 10:30 Panel 1: Systems and Pathways of Health Care for the Epilepsies: Existing Models and Opportunities for Improvement
Facilitators: Patty Shafer and Paul Jarris

9:00 – 9:05 Panel Introductions
9:05 – 9:15 The Patient Perspective
  Warren Lammert, Epilepsy Therapy Project
9:15 – 9:25 Epilepsy Centers
  Robert J. Gumnit, National Association of Epilepsy Centers
9:25 – 9:35 VA Epilepsy Centers of Excellence
  Karen Parko, San Francisco VA Medical Center
9:35 – 9:45 UK System: Lessons Learned
  Helen Cross, Great Ormond Street Hospital for Children
  (via phone)
9:45 – 9:55 Clinical Pathways: Health System Perspective
  David Nerenz, Henry Ford Health System
Questions:

- **What experiences do people with epilepsy and their families have when entering and moving through the health care system? What challenges do they confront, and how are they overcome?**

- **What are the current pathways and models of care for people with epilepsy in your health system? What are the current models of care for specific populations with epilepsy, including children, women, older adults, and racial and ethnic minorities?**

- **How do people with epilepsy move through your health system? What is known about the time to treatment and referral for people with epilepsy in your health system?**

- **How is care coordinated for people with epilepsy? What is the role of epilepsy specialists in your health system?**

- **How do you measure quality of care in your health systems? What strategies do you use to ensure access to care in your system?**

- **What is known about health outcomes for people with epilepsy treated in your health system?**

- **What international models of care for people with epilepsy have lessons learned that could be applied to the United States?**

- **What are your priority recommendations for improving systems of care to better meet the needs of people with epilepsy?**

10:30 – 10:45 Break

10:45 – 12:15 p.m. Panel 2: Health Care for the Epilepsies: Quality of Care

Facilitators: Ramon Diaz-Arrastia and Carolyn Cocotas

10:45 – 10:50 Panel Introductions
10:50 – 11:00 Treatment Guidelines and Comparative Effectiveness Research
  
  *Jacqueline French, New York University*

11:00 – 11:10 Medication Issues: Brand vs. Generic AEDs
  
  *Michel Berg, University of Rochester*

11:10 – 11:20 Lessons Learned from the Implementation of Performance Measures and Centers of Excellence for the Care of Stroke Patients,
  
  *Marilyn Rymer, Saint Luke’s Brain and Stroke Institute (via phone)*

11:20 – 11:30 New Models in Health Care Services Delivery and Reimbursement
  
  *Benjamin Druss, Emory University*

11:30 – 12:10 Committee Questions and Discussion
12:10 – 12:15 Concluding Remarks and Panel Summary

Questions:

- **What further efforts are needed on epilepsy treatment guidelines and parameters for care? How are treatment guidelines evaluated? What comparative effectiveness research exists for best practices?**
• How are performance measures endorsed, and instituted?
• What is known about the efficacy of brand versus generic AEDs? How does this impact access to medications?
• How do reimbursement issues impact access to care?
• How could health care reform affect the access to and quality of care for people with epilepsy?
• What innovative approaches are needed to improve health care?
• What is the future for models of care in light of the 2010 Patient Protection and Affordable Care Act?
• In your perspective, what makes up appropriate care for people with epilepsy in regards to services and personnel?
• What are your priority recommendations for improving quality of care and access to care for people with epilepsy?

12:15 – 1:00 Lunch

1:00 – 2:30 Panel 3: Health Care for the Epilepsies: Access and Barriers
Facilitators: Sandy Cushner-Weinstein and Lionel Carmant

1:00 – 1:05 Panel Introductions

1:05 – 1:15 Overcoming Disparities in Access to Care for Underserved Populations
Jorge Burneo, University of Western Ontario

1:15 – 1:25 Barriers to Access
Charles Onuffer, University of Illinois at Chicago (retired)

1:25 – 1:35 Lessons Learned from the Epilepsy Learning Collaborative
Deanna McPherson, HRSA

1:35 – 1:45 Care Coordination: Improving Transitions and Coordination Between Health Care Providers and Intersections with Community Services
Diane Carter, University of Virginia, Care Coordination for Children

1:45 – 1:55 Innovative Approaches to Improving Access to Care
Jeanette Hartshorn, Telemedicine Epilepsy Management Program of Texas

1:55 – 2:25 Committee Questions and Discussion

2:25 – 2:30 Concluding Remarks and Panel Summary

Questions:
• What are the barriers to access and care across populations? For specific populations? What disparities in care exist currently?
• What lessons have been learned about improving access and eliminating disparities? What are possible solutions to overcome these barriers?
• What is known about whether the current workforce is adequate to provide quality health care for people with epilepsy?
• How might changes in technology (e.g., telemedicine) impact access to care?
• What successful models exist for integrating the care of risk factors, co-morbidities, and sequelae in people with epilepsy?
• What needs to be done to improve care coordination encompassing health care, mental health care, education, employment, and other services? What are your priority recommendations for improving access to care and reducing health disparities for people with epilepsy?

2:30 – 2:45
Break

2:45 – 4:15
Panel 4: Education of Health Care Professionals
Facilitator: Greg Holmes

2:45 – 2:50  Panel Introductions
2:50 – 3:00  Educating Neurologists and Epileptologists
            David Labiner, University of Arizona
3:00 – 3:10  Educating Primary Care Providers
            Paul Levisohn, University of Colorado
3:10 – 3:20  Nursing Education
            Janice Buelow, University of Indiana
3:20 – 3:30  Psychiatry
            Deborah Hales, American Psychiatric Association
3:30 – 3:40  Geriatrics
            Ilo Leppik, University of Minnesota
3:40 – 4:10  Committee Questions and Discussion
4:10 – 4:15  Concluding Remarks and Panel Summary

Questions:
• What are the current approaches being used to educate and test knowledge and competence of health care professionals about the epilepsies?
• Are there core competencies and/or curricula currently available that focus on the epilepsies?
• How much time is devoted to teaching information relevant to the epilepsies? At what level of detail is the information taught?
• What role does continuing education play in educating health care professionals about the epilepsies?
• How could technology be used to expand and improve education opportunities and provide decision support for health care professionals who work with people with epilepsy?
• What are the best strategies for educating health care professionals about clear communication and effective interactions with patients who have epilepsy?
• What are the barriers and challenges to improving education of health care professionals about the epilepsies? How can these barriers be overcome?
• What are your priority recommendations for improving the education of health care professionals about the epilepsies?
4:15 – 5:45  Panel 5: Education of Patients and Families
Facilitators: Joan Austin

4:15 – 4:20  Panel Introductions
4:20 – 4:30  Successful Patient and Family Education
   Kate Lorig, Stanford University
   (via phone)
4:30 – 4:40  Educating Patients in Health Care Settings
   Mimi Callanan, Stanford University
4:40 – 4:50  Education for Self-Management
   Colleen Dilorio, Emory University
   (via phone)
4:50 – 5:00  Ensuring Health Literacy and Cultural Appropriateness
   Cheryl Bettigole, Philadelphia Department of Public Health
5:00 – 5:10  The Role of Technology in Educating Patients and Families
   Michael Wolf, Northwestern University
5:10 – 5:40  Committee Questions and Discussion
5:40 – 5:45  Concluding Remarks and Panel Summary

Questions:
• What are the health care (psychosocial as well as medical) education needs of patients? Of families? Where are the gaps in knowledge? How can interventions be aimed at these gaps?
• What are the critical junctures for educating patients and families about the epilepsies?
• How can successful education efforts improve self-management?
• What are the roles for health care providers, foundations and organizations, and community programs in ensuring that patients and families are well educated and informed about the epilepsies?
• What are the key components and best practices required for developing successful patient and family education programs?
• What are the challenges and barriers for developing successful patient and family education interventions and programs?
• How can new technology, online resources, and social media tools effectively be used to improve patient and family education?
• What are the best strategies for ensuring that education interventions are targeted appropriately in terms of health literacy and cultural sensitivity?
• What are your priority recommendations for improving the education of patient and families about the epilepsies?

5:45 p.m.  Adjourn—The workshop will reconvene at 8:15 a.m. on Wednesday
8:15 a.m. **Welcoming Remarks**  
*Mary Jane England, Committee Chair*

8:30 – 9:00 **Public Testimony**  
Moderator: *Mary Jane England*  
- John Pellock, *American Epilepsy Society*  
- Robert Moss, *SeizureTracker.com*  
- Sinead Aylward  
- Richard Leslie, *Wyoming Epilepsy Association*  
- Mary Jo Pugh, *Veterans Health Administration*  
- John Gambo  
- Michael Bornemann  
- Sabrina Cooke

9:00 – 10:30 **Panel 6: Improving Quality of Life: Community Programs and Resources**  
Facilitator: Dilip Jeste

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<tr>
<th>Time</th>
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<tbody>
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<td>9:00 – 9:05</td>
<td>Panel Introductions</td>
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| 9:05 – 9:15 | Mental Health Services and Resources Across the Lifespan  
*Naomi Chaytor*, University of Washington  
(via phone) |
| 9:15 – 9:25 | School-Based Services and Resources  
*Bruce Hermann*, University of Wisconsin |
| 9:25 – 9:35 | Vocational and Employment Services and Resources  
*Robert T. Fraser*, University of Washington  
(via phone) |
| 9:35 – 9:45 | Independent Living Resources and Services  
*Rebecca Rubin*, Jewish Foundation for Group Homes |
| 9:45 – 9:55 | Other Community Resources  
*Patricia Gibson*, Wake Forest University |
| 9:55 – 10:25| Committee Questions and Discussion                                        |
| 10:25 – 10:30| Concluding Remarks and Panel Summary                                     |

Questions:
- What mental health services and resources (including psychosocial and mood issues) are available for people with epilepsy and their caregivers? What services exist for people with psychogenic seizures?  
- What school-based services and resources (e.g., IEPs) exist for children and young adults with epilepsy to address cognitive and developmental issues, including learning and behavioral problems? How are program employees educated about epilepsy?  
- What vocational and employment services and resources exist for people with epilepsy? What exists for young adults transitioning from school to the workforce? How are cognitive problems related to employment handled? How are employers educated about epilepsy?  
- What resources and services exist to support independent living for people with epilepsy? How are cognitive and geriatric issues handled?
• What general community resources and services currently exist for people with epilepsy? What opportunities exist to support the participation of people with epilepsy in society? What programs exist specifically for children and young adults? For seniors? For other specific populations?

• How successful are these programs? What is known about the impact of these programs on the quality of life of people with epilepsy and their families?

• What are the gaps and opportunities for improvement?

• What are your priority recommendations for improving community care programs to better meet the needs of people with epilepsy?

10:30 – 10:45 Break

10:45 – 12:15 p.m. Panel 7: Beyond Stigma: Public Education and Awareness Campaigns
Facilitator: Vicki Beck

10:45 – 10:50 Panel Introductions

10:50 – 11:00 Epilepsy Education and Awareness Campaigns: Successes, Challenges and Next Steps to Reduce Stigma
Sandy Finucane, Epilepsy Foundation

11:00 – 11:10 Global Mental Health Programs: Progress, Lessons Learned, and Recommendations to Reduce Stigma
Bernice A. Pescosolido, Indiana University

11:10 – 11:20 Social Marketing Campaigns: Impact on Mental Health Stigma
Chris Marshall, SAMSHA

11:20 – 11:30 Advocacy Efforts to Reduce Mental Health Stigma
Robert Carolla, NAMI

11:30 – 11:40 Leveraging Media to Reduce Stigma: Broadcast, Print, Internet and User Generated Sites
Otto Wahl, University of Hartford

11:40 – 12:10 Committee Questions and Discussion

12:10 – 12:15 Concluding Remarks and Panel Summary

Questions:

• Please describe public education and awareness campaigns that your organization has been involved with. What were the outcomes of the campaign and how was success measured?

• How can public education and awareness campaigns be used to increase knowledge and understanding about the epilepsies, change attitudes and perceptions, and reduce stigma?

• What are the key components and best practices that are required to develop a successful public education and awareness campaign?

• How can online tools and social media effectively be used for public education and awareness campaigns?

• What are the challenges and barriers for developing a successful public education and awareness campaign for the epilepsies?

• What is the role of the media in educating the public and how can this role be leveraged to better educate the public about the epilepsies?

• What are your priority recommendations for improving the education of the public about the epilepsies?
12:15  Closing Remarks  
Mary Jane England, Committee Chair

12:30 p.m.  Open Session Adjourns