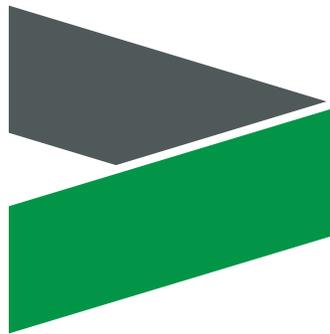


First Annual International Symposium on Autoimmune Encephalitis

Discussions, Conclusions and Next Steps



Durham, NC (USA) | March 27-28, 2014

AE**ALLIANCE**.ORG



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This symposium was funded with the proceeds from the Florence Forth Road Race held in Durham, NC on March 1, 2014.

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WHAT IS THE AE ALLIANCE?

The Autoimmune Encephalitis Alliance was founded in December 2012 by families with a shared vision of a different future for autoimmune encephalitis. The AE Alliance board consists of Will and Leslie McDow, Daniel Egger and Susannah Cahalan, author of *Brain on Fire*. Dr. Helen Egger, also a founding member of the AE Alliance, serves as chair of the AE Alliance's Science Advisory Board. Together these families launched the Autoimmune Encephalitis Alliance to change how patients with autoimmune encephalitis are diagnosed and treated, to support families coping with the disease, and to promote new scientific and clinical research that will lead in time to a cure.

A BOLD AND SIMPLE VISION: A CURE FOR AUTOIMMUNE ENCEPHALITIS ACCESSIBLE TO ALL.

The AE Alliance, a 501c3 nonprofit organization based in Durham, NC, seeks to improve the lives of AE patients and their families by:

- Establishing clinical standards of care across medical disciplines.
- Coordinating basic and clinical research efforts.
- Building community awareness and connecting families so nobody faces autoimmune encephalitis alone.



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EXECUTIVE SUMMARY

The Autoimmune Encephalitis Alliance hosted experts from around the world for the first annual International Symposium on Autoimmune Encephalitis held March 27-28, 2014. This symposium connected clinical scientists and researchers from a wide variety of medical fields and institutions. This meeting was the first significant step toward the extensive collaboration needed to expand diagnosis, improve treatment and accelerate a cure for autoimmune encephalitis (AE)

The symposium created new connections, advanced discussion of AE diagnosis and treatment and galvanized AE experts to work together to improve care for AE patients and their families. The formation of the International Autoimmune Encephalitis Working Group is a powerful statement of the interest and dedication of clinicians and researchers seeking to improve AE care. The Autoimmune Encephalitis Alliance will enact the next steps identified in Section III by engaging and coordinating with the broader AE community of patients, families, clinicians, researchers and other medical professionals over the coming months and years.

The symposium was funded through proceeds from the annual [Florence Forth](#) road race and with support from donors to the Autoimmune Encephalitis Alliance, including Walgreens Infusion Services.

This report summarizes the discussions and outcomes of the symposium in three sections.

Section I provides an introduction to the AE Alliance and symposium attendees.

Section II outlines the core areas of discussion from the symposium including A) shared perspectives on current status and future vision, B) definitions and diagnostic criteria, and C) challenges to AE treatment.

Section III describes the formation of a working group comprised of symposium attendees and outlines possible next steps and future considerations.

AUTOIMMUNE ENCEPHALITIS AWARENESS EVENTS

Immediately preceding the Symposium, the AE Alliance and Duke Medical Center hosted a series of AE Awareness Events with symposium attendees. These grand rounds, lectures and panel discussions can [be viewed online](#) and key points are included in this report where helpful to the discussion.



Susannah Cahalan author of NY Times bestseller “Brain on Fire” and AE Alliance Board Member. [Cahalan and other featured speakers are available on video.](#)

PAPERS PUBLISHED ON AUTOIMMUNE ENCEPHALITIS

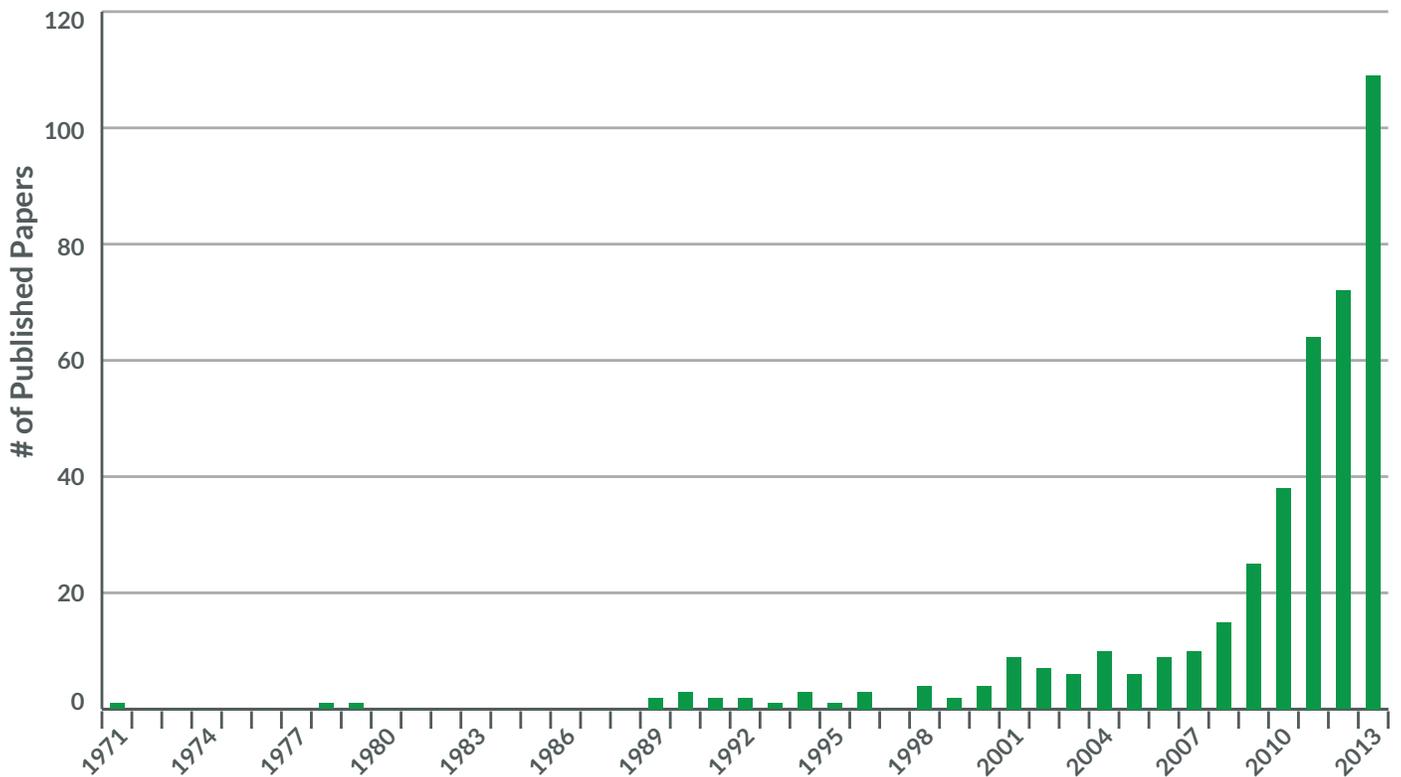


Figure 2. Number of papers published in PubMed by year using search term “Autoimmune Encephalitis.”

participants were challenged to express their views in ways that could be understood by other specialties and to promote a multidisciplinary approach to the disease.

Increased research has resulted in a dramatic rise in peer-reviewed journal articles over the past few years. Between 1970 and 1999, there were 26 papers published (as reported by PubMed.com using the search term “autoimmune encephalitis”). Then in the ten years between 2000 and 2009, 101 papers were published on autoimmune encephalitis. In 2013, a total of 109 papers were published – more than during the entire first decade of this century.

A network analysis of research papers published since 2009 found that symposium invitees were either the first or last author of 543 publications. (Note: not all publications focused on AE.) See Appendix C for graphic visualization of the network analysis. While symposium attendees have collaborated with many of the other attendees, the network analysis indicates an opportunity for a fuller collaboration among disciplines and institutions engaged on AE research. The symposium provided lengthy breaks and social time to foster these connections.

BETWEEN 2000 AND 2009, 101 PAPERS WERE PUBLISHED ON AUTOIMMUNE ENCEPHALITIS. IN 2013, A TOTAL OF 109 PAPERS WERE PUBLISHED—MORE THAN DURING THE ENTIRE FIRST DECADE OF THIS CENTURY

SECTION II: UNDERSTANDING, DEFINING & TREATING AE

The symposium was organized around three broad agenda items: 1) current and future status of AE care, 2) shared definition of AE, and 3) challenges of AE treatment.

The symposium began with participants sharing their view of the current status of AE and their vision for the future care of AE patients. During the second day, participants spent several hours reaching agreement on the outline of a definition of AE. Finally, attendees discussed the shared challenges associated with treating AE. The results of these discussions are presented in the following subsections.

II.A: CURRENT STATUS AND FUTURE VISION

During the introductory session, participants shared their perspectives about the current status of medical care for AE and expressed views about the desired future. Clinicians, researchers and patient families spoke about many common perspectives and concerns. The following issues and feelings were raised about the current status.

- The most common view of the current condition was a sense of isolation. The discussion revealed that clinicians, researchers and families feel alone when facing AE, perhaps because of the general lack of awareness about the disease. Doctors remain isolated by different specialties and institutions and no formal structure encourages collaboration across disciplines. During the discussion, one doctor related to the loneliness shown in a photo of an ice fisherman sitting alone on a large frozen lake.
- Most discussion groups identified a general lack of clarity about how to treat and manage AE. The group also addressed inadequate standardized treatment protocols and a lack of well-defined paths for management of the disease in the short or long term.

- In addition, current therapies for AE are considered primitive and non-specific. Most AE therapies are borrowed from other immune-mediated illnesses and affect the immune system too broadly.
- Clinicians also identified a shared sense of responsibility. Doctors recognized that they currently have more questions than answers about AE. When a patient worsens and the doctor doesn't have a remedy, he or she feels frustrated, overwhelmed and further isolated.

Similarly, the group discussed views about the future of AE care. A sense of excitement about the potential future for AE care was shared among the participants:

- The future vision of AE care begins with collaboration. The best care requires multidisciplinary teams who can provide clinical management and research efforts within and across institutions. A future of collaboration-based care includes respect for colleagues (other clinicians, nurses, therapists, etc.) who are challenged by the complexity of this disease and respect for patients and families dealing with AE.
- Improved care also requires enhanced clarity. Research-based evidence is required to understand the underlying causes of this disease, which could lead to better-targeted therapy. Clinical standards of care will help define diagnosis and treatment pathways needed to bring clarity to AE treatment.
- Enhanced clarity leads to greater recognition of AE. Wide acceptance of AE as a serious and debilitating brain disease within the medical community will require dissemination of information about AE at multiple levels. Universal insurance approval is critically important for proper diagnosis and treatment of the disease.
- Improving the future of AE care requires better tools. Doctors need standardized clinical guidelines, better ways of confirming the diagnosis, and safer, more effective therapies. Increased research is required to develop new diagnostic and treatment options.

The group concluded that it is not satisfied with the status quo. There is a feeling of urgency to move this disease into a future with more clarity and cooperation. All attendees are passionate about producing lasting

changes so that patients, clinicians and investigators can reach their full potential. With a common understanding of the current condition and a shared desire to change the future, the group undertook a discussion to define AE.

II.B: DEFINING AUTOIMMUNE ENCEPHALITIS

The participants agreed that a desired outcome of the symposium should be a statement about the definition and/or diagnostic criteria for AE. A standardized, widely accepted definition could lead to improved diagnosis, treatment and recognition of this disease. At the conclusion of the discussion about AE definitions, the group agreed to collaborate on a draft consensus statement based on a syndrome-specific approach to defining AE. Other efforts to define AE were identified, including Zuliani et al¹ and the World Health Organization.² These sources will be consulted in creating a consensus definition as will the work of the International Encephalitis Consortium.³ The attendees organized a working group to make progress toward a consensus definition. Below are the key points of discussion in defining AE.

- The target audience for a clear definition of AE should be both primary care physicians and specialists (i.e. neurologists, psychiatrists, rheumatologists). The attendees spent ample time balancing the scope of a definition. The group discussed the pros and cons of crafting the definition broadly versus narrowly. Broad criteria could avoid missing AE cases but could result in false positives (patients seeking treatment who don't have AE), while a narrower, more stringent criteria might reduce the number of referrals but could result in false negatives (patients being told they don't have AE when they do). The general, though not uniform, agreement of the group was to craft a definition that is broader and more inclusive. All participants recognized the critical need to maintain a rigorous, science-based definition.
- Similarly, several speakers expressed concerns about defining the borders of AE. There was uncertainty about whether to include patients with co-existing neurological illnesses or patients with slowly progressing disorders. Others questioned whether to include or exclude other steroid-responsive brain disorders (such as ADEM and vasculitis) or Pediatric Acute-onset Neuropsychiatric Syndromes (PANS). These

questions will be resolved through discussions about a definition.

- All agreed that a lack of neural autoantibodies should not be a barrier to the diagnosis or treatment of AE if other aspects of the definition are met. The group discussed how to incorporate the response to immunotherapy into diagnosis of AE. The attendees acknowledged that this approach to the management of AE was not yet widely accepted, despite published evidence that patients with autoantibody-negative AE respond to immunotherapy.^{4,5} The adequate minimum treatment trial should be defined, including types of therapy, sequence, dose and duration. Several attendees noted that if immunotherapy is delayed, a lack of response to treatment does not exclude a diagnosis of AE.
- Similarly, a family history of autoimmunity is considered helpful. However, if a patient does not have a family history it does not preclude him or her from having AE. Therefore, such a history should not be required for a diagnosis of AE.
- The group also noted that these syndromes present differently in adults versus children.^{4,6} Therefore, the definition needs to consider age-related differences. The extent of these differences is illustrated in Figure 3.

**THE FUTURE VISION OF
AE CARE BEGINS WITH
COLLABORATION. THE
BEST CARE REQUIRES
MULTIDISCIPLINARY
TEAMS WHO CAN PROVIDE
CLINICAL MANAGEMENT
AND RESEARCH EFFORTS
WITHIN AND ACROSS
INSTITUTIONS.**

To identify required aspects of a shared definition, the attendees listed some of the clinical clues to diagnosis patients with AE. The discussion included the following symptoms. This should not be considered a comprehensive list of AE symptoms or components of a definition.

- Diverse neurological and psychiatric manifestations, often multifocal, including disorders of memory, thinking, behavior and movement
- Sudden or rapid onset
- Rapidly progressive course
- Exclusion of a current or personal history of cancer (suggestive of a paraneoplastic cause of an autoimmune brain disorder)
- Exclusion of other illnesses
- Inflammatory markers in the cerebral spinal fluid (CSF)
- Evidence of a co-existing autoimmune illness

- Consistent or characteristic EEG findings
- Characteristic imaging results
- Family history of autoimmunity disease
- Neural-specific autoantibody in the serum or CSF
- Favorable response to a trial of immunotherapy

II.C : CHALLENGES IN TREATING AE

The attendees identified the lack of consensus in treatment protocols as a major challenge facing clinicians. Most agreed that corticosteroids and intravenous immunoglobulin (IVIG) are commonly used as first-line immuno-therapies. However, differences were noted in the choice of drugs, doses, frequency, duration and the combinations of different therapies. Participants noted the enhanced potential for increased toxicity from second-line therapies (rituximab, cyclophosphamide and mycophenolate mofetil), especially in combination with other drugs prescribed to treat AE symptoms (behavioral, psychotic, neurological, epileptic, etc). Attendees

FIRST SYMPTOMS BY AGE

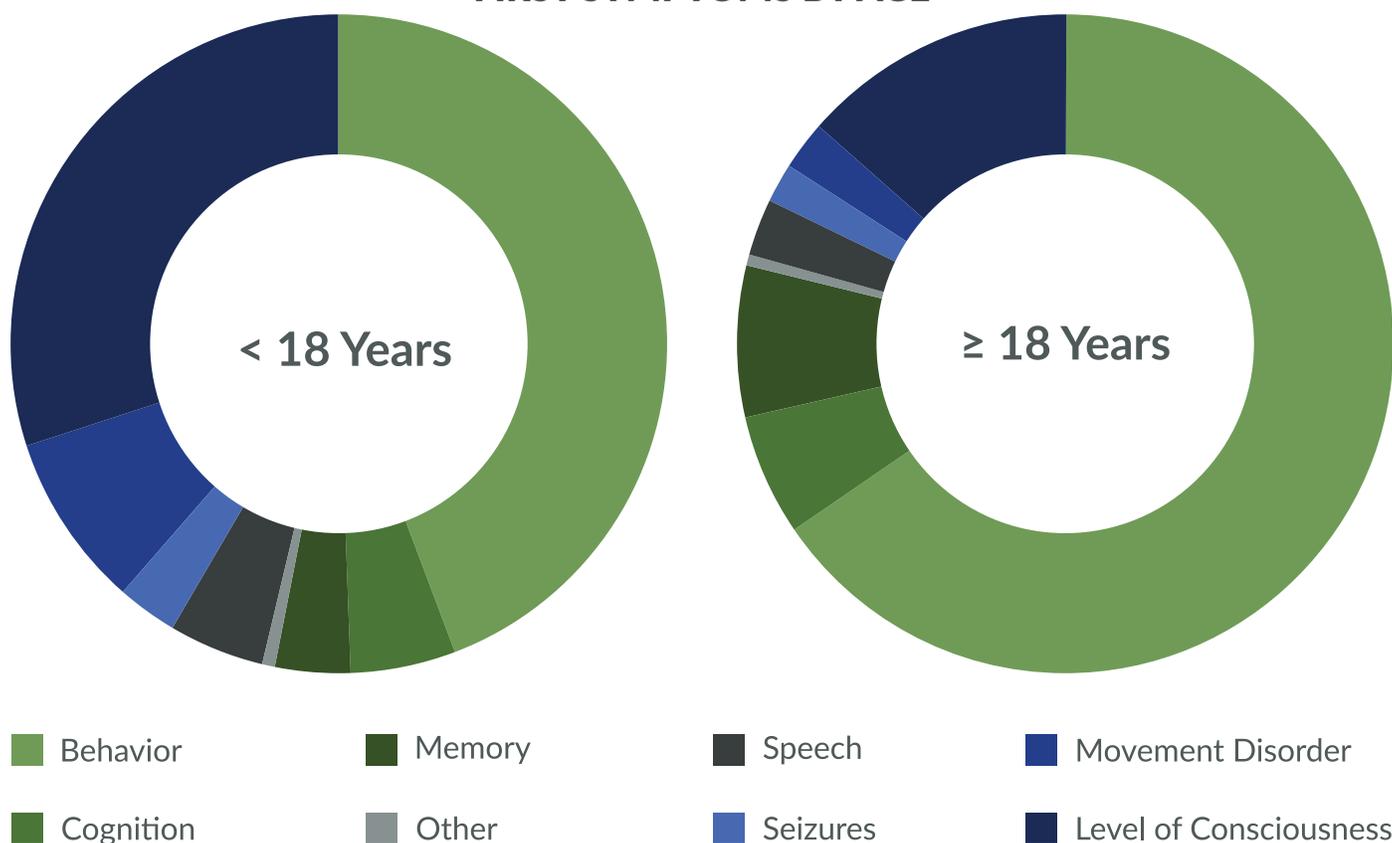


Figure 3: Initial symptoms of NMDAR encephalitis patients by age group. Source: Presentation by M Titulaer at Duke Medical Center, March 2014.

discussed the varied and inconsistent protocols for escalation and/or weaning of immunotherapy.

Some attendees identified the difficulty of coordinating the multi-specialty care that the complicated, prolonged course of AE can require. Likewise, care on general inpatient units can be difficult because medical staff often is not experienced in managing the psychiatric symptoms of some AE patients. In addition, the cost of care and the difficulty of obtaining insurance approval for immunotherapy creates issues for doctors and patients alike.

Clinicians often find it difficult to accurately track outcome measures. Some cognitive examinations, such as neuropsychological ranking scales, were considered time consuming and difficult to administer. Consequently, determining whether a patient has responded to treatment is challenging.

Post-hospital and rehabilitation care was identified as a shared challenge for both clinicians and families. Additional discussion, likely with experts in recovery, is needed.

SECTION III: OUTCOMES

IIIA: CONCLUSIONS

The symposium enabled new connections across disciplines, institutions and geographies. The meeting established a community that embraces collaboration and resulted in the formation of the International Autoimmune Encephalitis Working Group. The working group will reconnect in 12-18 months at the second annual meeting of the IAE Working Group.

The Working Group made substantial progress towards the preparation of a consensus definition for AE, including: 1) clarification of underlying issues, 2) selecting an existing definition of AE as a starting point, 3) deciding how that definition should be modified and 4) assuming responsibility for coordinating, drafting and submitting the statement to a peer-reviewed journal.

The Working Group identified many AE resources that should be shared to improve access to quality care. Over time, the AE Alliance will serve as the hub for aggregation of these materials including: 1) current treatment protocols, 2) diagnostic criteria or algorithms,

3) definitions of an adequate trial of immunotherapy, 4) ranking scales to access outcomes, 5) educational materials, 6) journal articles and 7) active research projects.

The AE Alliance has made efforts to establish an informal, preliminary referral network through contacts and conversations that occurred at the symposium. The AE Alliance and the Working Group will determine later the need and/or opportunity for a more formal clinical network through which patients can be referred to AE experts.

IIIB: NEXT STEPS

The AE Alliance is committed to help organize and expand access to quality medical care for all AE patients. The AE Alliance and the IAE Working Group are developing project-specific subgroups to address the following 12-18 month goals:

1. Prepare a consensus statement on the definition/diagnostic criteria for AE and submit that publication to a peer-reviewed journal.
2. Identify and develop AE referral centers with multidisciplinary areas of expertise (pediatric, adult, rheumatology, psychiatry, and neurology) and develop the process for patient referrals. With the support of the Working Group, the AE Alliance will develop a Clinical Network of AE specialist/experts to function as a referral service.
3. Collect useful educational material (manuscripts, curricula, CME material, video and slide presentations) to place on the Alliance website. Help the Alliance become a recognized resource for doctors seeking information about AE. Guide the Alliance's efforts to add information about AE to relevant curricula and develop webinars that award CME credits.

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- 2) World Health Organization. The International Classification of Diseases 11th Revision – Beta Draft. Full draft available at <http://apps.who.int/classifications/icd11/browse/f/en>. Definition of autoimmune encephalitis available at <http://id.who.int/icd/entity/241281019>. Accessed June 2, 2014
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APPENDIX A: PURPOSES, OBJECTIVES AND AGENDA

The symposium was organized and designed to make progress toward four objectives as described below.

PURPOSE & OBJECTIVES

The AE Alliance seeks to create common ground among a multi-disciplinary group of clinicians and scientists who care for patients and conduct research on autoimmune encephalitis. The purpose of the AE Symposium is to catalyze a cross-institution, multi-disciplinary initiative to improve the diagnosis and treatment of autoimmune encephalitis and advance research toward a cure.

The AE Symposium will provide a forum for a collaborative discussion of the following objectives:

- Characterizing the full range of presentations of autoimmune encephalitis.
- Identifying the most pressing clinical challenges in the diagnosis and treatment of autoimmune encephalitis.
- Collaboration on the development of comprehensive practice guidelines for the diagnosis and treatment of the full range of autoimmune encephalitides across the lifespan.
- Identifying the most promising research questions aimed at understanding the underlying pathophysiologies and etiologies of autoimmune encephalitis in order to find a breakthrough cure.

AGENDA

THURSDAY, MARCH 27TH

3:00 P.M. – 5:00 P.M.

Welcome, Introductions, Personal & Clinical Perspectives on the State of AE

5:40 P.M.

Meet in Marriott lobby to depart for reception and dinner

5:45 P.M.

Bus departs from the Marriott for reception and dinner at private home

6:00 P.M. – 9:00 P.M.

Reception & Dinner

FRIDAY, MARCH 28TH

7:30 A.M. – 8:30 A.M.

Breakfast / Coffee

8:30 A.M. – 10:15 A.M.

Work session & group dialogue focused on Objective #1

10:15 A.M. – 10:45 A.M.

Coffee & snack break / dialogue a.m.ong participants

10:45 A.M. – 12:15 P.M.

Work session & group dialogue focused on Objective #2

12:15 P.M. – 1:15 P.M.

Lunch

1:15 P.M. – 2:30 P.M.

Work session & group dialogue focused on Objectives #3, 4

2:30 P.M. – 3:00 P.M.

Bringing it all together: discussion of next steps & wrap-up

3:00 P.M.

Adjourn and depart

APPENDIX B: SYMPOSIUM ATTENDEES

BEAU ANCES, MD, PHD, MSC

Associate Professor, Department of Neurology
Washington University
St Louis, MO, USA

SUSANNE BENSELER, MD, PHD

Associate Professor, Department of Paediatrics, Pediatric
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Private Practice
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Journalist and Author of Brain on Fire
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Associate Professor, Discipline of Paediatrics and Child
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Group, Head of Movement Disorder Research
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AVA EASTON, PHD

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MARK GORMAN, MD

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SOUHEL NAJJAR, MD

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MARC PATTERSON, MD

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SEAN PITTOCK, MD

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Mayo Clinic
Rochester, MN, USA

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Assistant Professor of Medicine
Duke University Medical Center

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Active staff, Neurological Institute
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University of Oxford
Oxford, England

APPENDIX C: LEAD AUTHOR NETWORK ANALYSIS

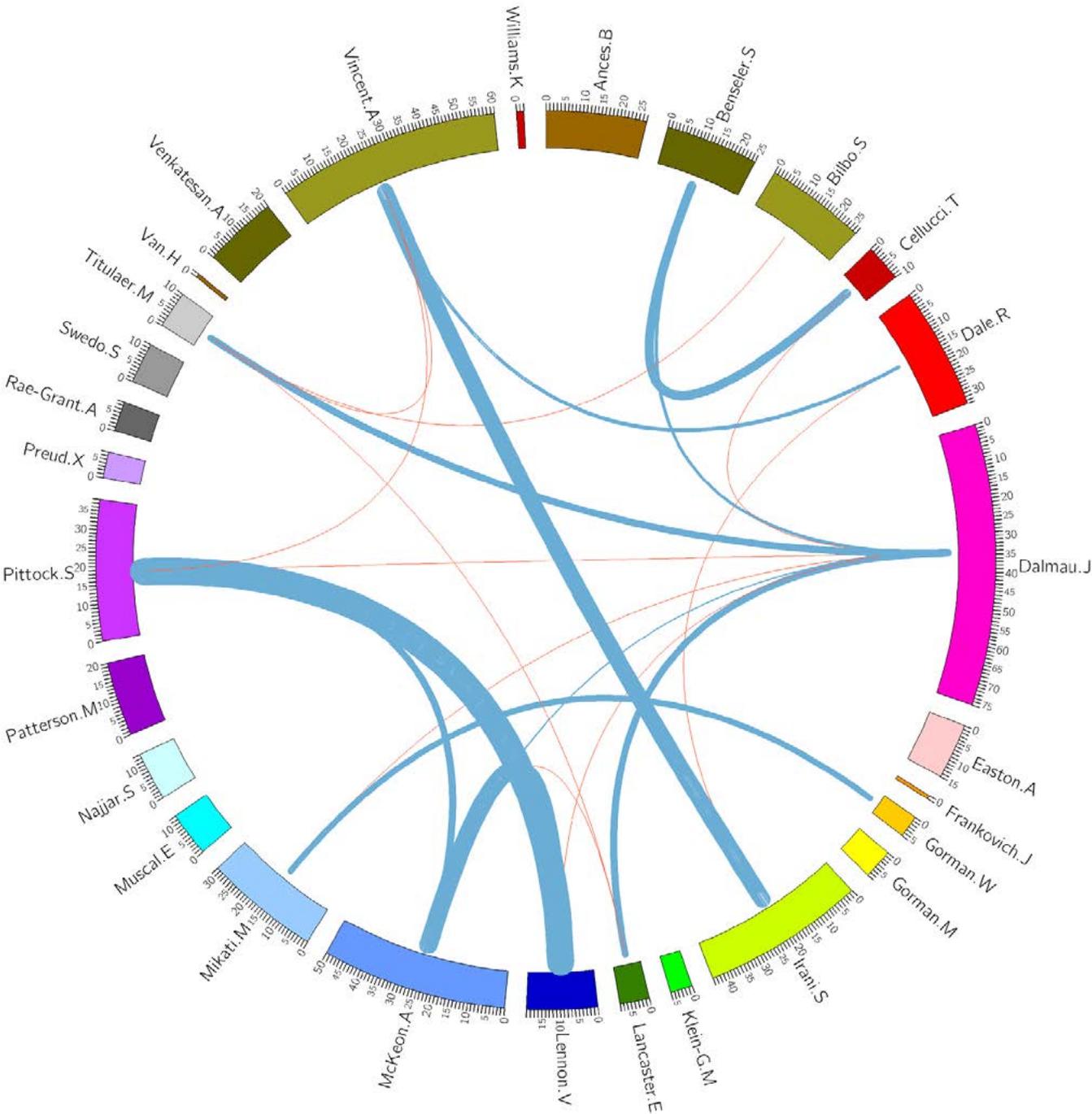


Figure 4

APPENDIX D: FUTURE ACTIVITIES

SUGGESTIONS FOR FUTURE CONSIDERATION

Throughout the symposium, numerous collaborative efforts were suggested to improve the future of AE. The suggestions that became concrete plans are described in Section III of the report. Additional suggestions are described below and will be pursued as resources become available.

- **Clinical trials** Clinical trials of therapies for AE are challenging because individual centers do not treat enough patients. It was suggested that collaborative centers could pool their patient populations for such studies.
- **Collaborative research** The different treatment protocols for AE could be standardized to a few mutually accepted protocols and tested collaboratively across institutions. This approach would provide the opportunity to conduct comparative effectiveness research, retrospectively.
- **Documentation of testing facilities for AE-linked autoantibodies** Clinicians requested a list of the laboratories that perform these tests with the services and relative merits of each laboratory. They need this type of information to select the best laboratories and to justify that selection to local hospital authorities. Differences between laboratories need to be documented in a way that can convince hospital pathology departments to send these specimens to the appropriate laboratory.
- **Sharing serum samples** Several attendees suggested sharing serum samples to evaluate and improve the quality of testing for autoantibodies. It was proposed that serum samples be collected from clinical centers through a central biobank and shared across research centers.
- **Development of local experts** Medical education through grand rounds and persistent on-site leadership is proven to promote behavioral change in doctors. A core set of travelling experts paired with local clinical leaders was proposed to provide local educational resources and maintain fluency in this changing field.

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