

ICARE Member Report

- **Vision 20-20**
Epilepsy voluntary and governmental organizations which, by joining together, develop projects that can be accomplished more efficiently than if the groups functioned separately and autonomously
- **The overall mission of Vision 20-20 is to improve the lives of patients and their families**
- ***Membership organizations growing annually***

ICARE Member Report: Vision 20-20

- Major topics of interest in epilepsy research
 - Many of the participating organizations support research programs that reflect the missions and goals of their individual organizations
 - Effort to distribute funds and general areas of research support in a balanced manner
 - Recognition of patient driven initiatives versus academic initiatives
 - Convergence
 - Divergence
- Types of research support or other activities (*e.g., training, meetings, networks, resources; please highlight examples of recent/current activities here*)
 - Coordinate research funding
 - Institute of Medicine Report
 - Development of a “Common Message” on epilepsy
 - Healthcare Reform
 - Cooperative approach to improve patient involvement in clinical research

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- **Resources available for shared use or other opportunities for collaboration**
 - **Resources in Epilepsy Research website: supported by AES and populated by the individual organizations**
 - online database of epilepsy funding opportunities with a listing of initiatives, application instructions and an inventory of currently-funded research
 - **Semi-annual meetings of group; interim phone conferences**
 - **Variable support and resources from member organizations depending upon task at hand**

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- **Priorities and/or plans for future activities**
 - **Reinforce and strengthen alliance**
 - Optimize forums for interaction, find niches, encourage stake-holding,
 - Maintain cohesion of group
 - **IOM**
 - Continue to serve as a clearing house for IOM requests during report development
 - Develop coordinated, complementary plans for dissemination of IOM Report
 - **Continue working on “Common Message”**
 - Ensure plurality of message for individual adaptation
 - Accurate referencing of compelling statistics for messaging
 - **Promote research**
 - Work on coordinating basic research funding
 - Encourage patient participation in epilepsy clinical trials and research
 - **Determine common responses to healthcare reform**