



Introducing Epilepsy Leadership Council

Vision 20-20 is now the **Epilepsy Leadership Council (ELC)**. At its December meeting, members voted on the name change and new administrative structure that will more accurately reflect the shared relationships among the organizations involved. By working together under a more formal structure, representatives of the 30+ professional organizations, disease-specific/patient advocacy organizations and governmental agencies will identify shared needs, set joint priorities, develop collaborative projects designed to provide support, shape policy, and stimulate research to improve the lives of individuals with epilepsy.

Since the founding of Vision 20-20, AES has provided administrative and staff support and will continue to do so for the ELC. AES is very supportive of this exciting new direction and pleased to have an ongoing role in the evolution of the Council. The importance of this affiliation was reaffirmed by the AES Board as a key relationship in support of strategic priorities for the Society in its leadership role in improving awareness of epilepsy and its impact and supporting collaboration around research in epilepsy.

The first Epilepsy Leadership Council Board was elected at the end of January. Congratulations to the following Representatives:

Grouping A: Professional Organizations

Christi Heck – National Association of Epilepsy Centers

David Labiner – American Epilepsy Society

Mary Jo Pugh -- Epilepsy Centers of Excellence, Veterans Administration

Grouping B: Patient Advocacy Organizations for the Epilepsies in General

Robin Harding – Citizens United for Research in Epilepsy

Angela Ostrom – Epilepsy Foundation

Grouping C: Syndrome Specific/Severe-End-of-the-Spectrum Patient Advocacy Organizations

Leslie Henkel – PCDH19 Alliance

Paul Karch - Dup15q Alliance

Barbara Kroner – Aicardi Syndrome

Ilene Miller – Hope for Hypothalamic Hamartomas

Lisa Moss – Tuberous Sclerosis Alliance

Christina SanInocencio – Lennox Gastaut Foundation

Grouping D: Organizations with missions especially concerned with mortality prevention and SUDEP

Stefanie Mingel – Danny Did