
Epilepsy Resources

Epilepsy Foundation

www.epilepsy.com

National charitable organization dedicated to the welfare of individuals and families impacted by epilepsy and seizures. Works to prevent, control, and cure epilepsy through community services, public education, federal and local advocacy, and supporting research into, new treatments and therapies. Also offers a Legal Defense Program through a fund.

Intractable Childhood Epilepsy Alliance

www.ice-epilepsy.org

Nonprofit organization dedicated to improving lives of children affected by intractable epilepsy through evidence-based information, advocacy for appropriate medical treatment (including compassionate use and orphan drug products), promotion of drug delivery, data collection through patient registries, and research funding leading to a cure.

Aicardi Syndrome Foundation

www.aicardisyndrome.org

Information gathering and sharing resource for professional and healthcare personnel and Aicardi syndrome families. Sponsors a biennial conference.

Angelman Syndrome

www.angelman.org

Works to advance awareness and treatment of Angelman syndrome through education and information, research, and support.

Batten Disease

www.bdsra.org

Batten Disease Support and Research Association
Dedicated to funding research, providing family support services, raising awareness, and advocating on behalf of those with Batten disease and their families and caregivers. The largest support and research organization dedicated to Batten disease in North America.

Charlie Foundation for Ketogenic Therapies

www.charliefoundation.org

Nonprofit organization that raises money for scientific research, education, and public awareness of diet therapies for epilepsy. Offers education, programs, and materials for caregivers, dietitians, and physicians, and hospitals.

Dravet Syndrome Foundation

www.dravetfoundation.org

Dedicated to aggressively raising research funds for Dravet syndrome, a rare and catastrophic form of epilepsy beginning in childhood, and related conditions.

LGS Foundation (Lennox-Gastaut Syndrome)

www.lgsfoundation.org

Not-for-profit organization dedicated to providing information about Lennox-Gastaut Syndrome, a rare and severe form of childhood onset epilepsy, while raising funds for research, programs, and services for individuals living with LGS, and their families.

Rett Syndrome

www.rettsyndrome.org

International Rett Syndrome Foundation/ Rettsyndrome.org
Focused, comprehensive research and family empowerment in regard to Rett syndrome and related MeCP2 disorders.

Rett Syndrome Research Trust

www.rsrt.org

Accelerates the development of treatments and cures for Rett Syndrome and related MECP2 disorders.

Sturge-Weber Foundation

www.sturge-weber.org

International nonprofit organization established for support, referral, advocacy, and research into the management and cause of Sturge-Weber syndrome. Also serves parents, professionals, and others concerned with Klippel-Trenaunay syndrome and port wine stain.

Tuberous Sclerosis

www.tsalliance.org

Tuberous Sclerosis National nonprofit voluntary health organization dedicated to finding a cure for tuberous sclerosis while improving the lives of those affected.