

# Each year, more Americans are diagnosed with epilepsy than Parkinson's, cerebral palsy and multiple sclerosis combined.

Dear Friend of Epilepsy Alliance,

That is a shocking statement but not a surprise to those of us who battle epilepsy every single day. Yet despite the number of people affected by epilepsy, it is one of the most under-funded medical conditions. The current tough economic times haven't helped. Unemployment rates are at a historical high. State budgets have been cut to the bare minimum. Foundations and corporations have tightened their belts; which translates into fewer grants and decreased support toward nonprofit organizations that provide much needed services. We have all felt the impact.

Each year there is an estimated one new epilepsy diagnosis every three minutes.

In the meantime, the rate of epilepsy diagnosis has not diminished. Nor has the need for services and support required by those affected. In fact, if anything, their need – YOUR need – has increased. The demand is high but the funding supply is low.

Yes, times are tough. There will be many changes as our country lifts itself out of this economic slump. However, I want to stress that one thing remains unchanged. The [Epilepsy Alliance of Orange County](#) is still here for you. We exist for one reason only, and that is to serve you, our constituents, as you turn to us for both information and support. We are moving ahead. We are making a difference. We are continually trying to enhance and expand the services and programs we can offer you.

Despite the economic impact on our organization, EAOC has remained focused on its mission to improve lives through education, support, and advocacy. Over the past year, progress has been made to build a stronger organization that is working toward the future so you and your children will live with less stigma and an increase in support and services to enhance your day-to-day lives.

In response to the needs identified in our July 2009 survey, EAOC has improved service delivery to adults with epilepsy and to parents of children with epilepsy. In addition to our very popular support groups, highlights of our efforts include:

- working collaboratively with the Department of Education to resolve the issue of administering Diastat® and other seizure rescue medications in the schools by non-licensed staff and advocating on behalf of our parents to ensure their children are provided appropriate educational opportunities;
- developing the *only* comprehensive hands-on interactive [Diastat® training program](#) utilizing mannequins for hands-on experience and with trainers personally trained by the drug manufacturer;
- actively working with other stakeholders like Epilepsy California, the Epilepsy Foundation and government officials to advocate for legislation to assure all necessary emergency medications are clearly covered by state regulations so further misinterpretation will be a thing of the past;
- fostering partnerships with local physicians, hospitals and other organizations serving individuals diagnosed with other disorders that include a co-diagnosis of epilepsy to coordinate support services and help people with epilepsy manage their health and lead independent, fulfilling lives;
- developing a “First Responders” program to provide support and information to newly diagnosed individuals and their families so they may start their epilepsy journey on the right foot and with a support system to help them on their way;
- increasing our community outreach efforts so others learn about epilepsy, thereby reducing the stigma associated with an epilepsy diagnosis;
- providing seizure recognition and seizure first aid training in schools and in business locations so our children have a safer place to learn and our adults have a safer place to work;
- adding online support groups for adults as well as for parents of children with epilepsy;
- working collaboratively with other nonprofit organizations that provide some vocational and independent living services to adults with disabilities.

Yes. We have been busy and I am pleased with our progress. While there is certainly no shortage of things to do, we have made great strides. Still, we have a long way to go.

30% of people diagnosed with epilepsy have persistent seizures despite treatment.

The severity of epilepsy varies for each individual. Some people are lucky enough to have seizure control with minimal medications. Others, unfortunately, continue having seizures despite taking many medications and trying many different therapies. People with epilepsy, whether controlled or not, may struggle daily due to their epilepsy or side effects of their medications. They face challenges like obtaining the right educational and recreational services, getting and keeping a job, finding transportation,

obtaining affordable medical insurance, living safely and independently. Until we cure the many aspects of epilepsy, we will all share the feeling of wanting to do more and to have it done yesterday. That's why the need for services is more critical than ever.

That's where EAOC can help and why I am asking for your support. We can't move toward the future without your help.

Like other nonprofits, EAOC has been hit hard by declining contributions and support from foundations and corporations that normally support our programs. Yes, the economy has hit us all. But it hits organizations like ours the hardest.

If you have donated before, we thank you for your support and hope you will once again be generous with your gift. If you have not had the opportunity to donate in the past, we hope you will consider the value of the services EAOC offers you and your family and give as generously as you can. We know times are tough, but if everyone gives something - whatever amount you can afford - we will pull through together.

I've enclosed our new brochure. I'm hoping it will give you a taste of what our organization is all about.

Best wishes for a happy holiday season,

Judith Pennella  
Executive Director  
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714 557 0202, ext. 104

P.S. Please take a moment to complete the attached reply form and return it with your **tax deductible** gift. Or you may donate online at <http://epilepsyalliance.org/html/donate.html>. Your gift of \$25, \$50, \$100 or more will help us continue our programs and provide the services people with epilepsy need to help experience a brighter future.

### How will your donation help?

85% of every dollar you donate is spent **entirely** on providing the highest quality, meaningful programs and services to help those impacted by epilepsy. The remainder covers the expense of running a legitimate nonprofit 501(c)(3) organization like – expenses like rent for office and meeting spaces, utilities, payroll, insurance, copying, postage, etc..

- \$25 is the cost of **one Epilepsy 101** training session
- **\$95** is the cost of **one First Responder Visit** for newly diagnosed patients.
- **\$150** is the cost of **one Diastat®/Seizure Recognition Training** session at one school so teachers can provide proper care for children with epilepsy.
- **\$193** is the cost of providing **childcare & music therapy** at each support meeting
- **\$250** is the cost of **one monthly educational and support meeting for Adults with Epilepsy.**
- **\$537** is the cost of **one monthly Parent Group meeting.**