

**One day = 86,400 seconds. Balance the equation. Seize the day.**



**EPILEPSY FOUNDATION  
ANNUAL REPORT  
2006/2007**

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## Message from the President of the Board of Directors

Our theme of seize the day serves as a phrase of encouragement to our many consumers and clients whose seizures and related conditions unpredictably rob them of hours, minutes or seconds from their day and of opportunities in their lives.

In our view, one full day = 86,400 seconds of seizure-free living, and our goal is to help our consumers and clients keep this equation, and their lives, as close to balanced as possible.

While our professional staff is involved 24/7 with our programs and our residence facilities, our board's activities are more along the lines of seizing opportunities for our long-term health and making sure the agency keeps its philosophical and financial balance as it grows.

The Epilepsy Foundation, based on its 2006 financial audit, faced a deficit for the first time in its 30-year history, presenting a challenging balancing act to the board and the staff.

In 2006, our program growth was significant. Any enterprise – profit and non-profit alike – must balance market/consumers' needs with fiscal responsibility. However, as a non-profit social services agency, we can not be timid about establishing new programs and services when the need is demonstrated; hence, we often look at a longer horizon to financial sustainability and/or to balance a lower yielding program against one with a higher yield. The good news is that we are optimistic that our 2007 operating budget will do much better.

One reason for the Epilepsy Foundation's growth is that our services are "transferable". The expertise we've already developed in counseling and support, family programs, case



David W. Milliman  
*President & CEO*



Stuart Gebell  
*President, Board of Directors*

was executive director of the Yates County ARC. David assumed his duties with us in February of 2007 and provides day-to-day and long-term leadership to our growing staff.

In 2007, the Epilepsy Foundation turns 30, and we hope you take the opportunity to read our short piece on the founding of the agency, and then go to our web site at [www.epilepsy-uny.org](http://www.epilepsy-uny.org) to see some of the original historical documents that led to our founding.

Stuart Gebell  
*President of the Board of Directors*

## Message from the President and CEO

On February 19<sup>th</sup>, 2007 I began my tenure as President and CEO of the Epilepsy Foundation after spending 26 years as executive director of the Yates County Chapter, NYSARC, Inc.

I offer my thanks to Sheila Appleby and the fine Epilepsy Foundation staff and Board of Directors for having the vision and determination to invest in new services and growth for the future of the Foundation and the people we serve.

As we go forward and build on previous successes, our focus will be on epilepsy, the fiscal strength of the agency, need-based and person-centered services, and making the Epilepsy Foundation a career of choice for the staff on which we depend to deliver needed services.

Our mission of helping people with epilepsy and related disabilities reach their potential will be carried out in our entire service area of 22 counties from Rochester to Syracuse to Binghamton.

This will be an exciting time for the Epilepsy Foundation and I am proud to play a part in making the future of the Epilepsy Foundation a solid success.

David W. Milliman  
*President & CEO*

### 2006 Revenues and Support

Government Contracts	\$ 615,222
United Way	\$ 47,564
Contributions	\$ 132,939
Medicaid & Service Fees	\$ 2,505,354
Special Events	\$ 100,447
Investments & Other Income	\$ 56,219
<b>Total</b>	<b>\$ 3,457,745</b>

### 2006 Expenses

Program services	\$ 2,973,855
Management	\$ 613,342
Fundraising	\$ 61,865
Other	\$ 2,319
<b>Total</b>	<b>\$ 3,651,081</b>





# 86,400 seconds

## SERVICE HIGHLIGHTS

Following are the major categories of our programs and services and summaries of their 2006 activity (and a few projections for 2007).

### Community Education

Through presentations on epilepsy to students and school staff, civic groups, companies and corporations, and other human service agencies, our educational activities teach awareness, response, understanding and acceptance.

In 2006, more than 3,200 individuals in the greater Rochester area learned more about epilepsy directly from us, a number comparable to previous years. We conducted 77 classroom/school presentations and 33 training presentations, and participated in three health fairs.

In Syracuse and Binghamton, 107 and 50 presentations were given in 2006, reaching approximately 3,000 and 1,400 individuals, respectively. In Syracuse, the popular "Train the Trainer" program reached school nurses throughout the region and is again offered in 2007.

### Information and Referral

*These days, no agency exists in a vacuum. We work with other human services agencies on a continuous basis to find the best resources to meet the needs of those who inquire.*

In 2006, the Foundation received 544 calls for information and referral from the Rochester region, 345 calls from the Syracuse region, and 168 from the Binghamton region.

### Family and Individual Support Services

*With support groups for both families and individuals, the Epilepsy Foundation facilitates people sharing and helping.*

Currently, we run support groups for young adults with traumatic brain injury and for parents of children who have TBI as well as groups for parents of children with epilepsy and for individuals with epilepsy. The Syracuse support group and Parent Family Network involved 94 people in group activities. The Binghamton support group and PFN involved 52 people.

Other measures of these services in 2006: 13 families received a total of \$11,000 in STRESSpite services and assistance; 27 families in Rochester received \$6,400 in funds from the Family Reimbursement Program; and seven families received help through the NY State Cares program for a total of \$4,250.

2006 also saw the introduction of the Segar Scholarship Awards, jointly funded by board member Stephen Segar and the board of directors, which help high school seniors with epilepsy with tuition for college or vocational training.

### Camp EAGR

*Our camp offers children and teenagers with epilepsy a chance to enjoy a traditional summer camp experience.*

Last summer, 71 kids (see photo above) enjoyed their week-long stay at Camp EAGR, situated at the YMCA Camp Weona in Warsaw, New York. With the help of WROC-TV 8, we produced a new video that will help us recruit new campers and cultivate additional donors.

### Residential Programs

*It is our goal that every Epilepsy Foundation consumer lives as fully and as independently as possible. Helping to make that happen are our residential facilities and services.*

The Epilepsy Foundation now has four community residences in Rochester – Howitt House, Wagner House, the Individual Residential Alternative Program at Rustic Village, and the newly opened Sheila's House in the Rochester suburb of Henrietta. These facilities provide a home to a total of 42 individuals with epilepsy and related disorders.

### Employment Solutions

*A job gives one a sense of self-worth and belonging, important benefits to those whose ability to enter the workforce is not always immediately recognized.*

In 2006, 62 adults participated in the Epilepsy Foundation's Job Club and Employment Club; of these, 36 maintained continuing employment and the remainder were developing their job search skills. A newer program, School-to-Work, served 25 high school students, helping them develop career goals and a plan for searching for meaningful employment.

In the fall of 2006, the agency's Good Grades Pay program received an award from Rochester Mayor Robert Duffy and New York State Assemblyman Joseph Robach. In 2007, the Epilepsy Foundation will be part of a three-year \$1.4 million grant to provide employment development and college enrollment programs to high school students with disabilities in the Rush-Henrietta and Brighton school districts in Rochester.

### Community Habilitation

*Our habilitation services teach, reinforce and restore the skills of daily living so necessary for a feeling of independence.*

In its third year, this program served 45 individuals in 2006 and enrollment is expected to remain steady. In 2007, we expect to announce a second program of habilitation that shifts much of the teaching and learning from the consumer's residence to settings out in the larger community.

### Case Management and Service Coordination

*Navigating the maze of social service programs is made much easier with the expertise of staff from the Epilepsy Foundation.*

Our service coordination and case management programs help consumers and clients qualify for Medicaid, OMRDD, and Department of Health service and waiver programs, such as those for TBI services. In 2006, 222 individuals in Rochester were served through these programs and the expectation is for that number to increase in 2007. In Syracuse, 52 people received service coordination, and in Binghamton, 10.

The Binghamton office continues to benefit from the generous support for operational expenses from Senator Tom Libous. In addition, a grant from the UW of Broome County, which overlapped with a grant previously provided by Eisai pharmaceuticals, enhanced support specifically to the case management service.

The 222 in Rochester included 35 people with brain injury served by our community integration counseling and intensive behavioral programs and 18 individuals with independent living skills training. Syracuse is just beginning to offer these kinds of services.



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## Six memos that changed our world...

In May of 1976, Xerox employee Patricia Ladd began a six-month paid social service leave so she could start a community organization that would help parents of children with epilepsy organize and plan for services and mutual support. During her leave, she pursued her activities from an office in Rochester's Health Association under the guidance of HA director James Dunphy. She's pictured (center) with her husband, William Thurston, and her daughter, Susan Ladd, at the 2007 Chocolate Ball, some 30 years after she got the Epilepsy Foundation started.

Pat was required to file monthly reports on her progress in starting the agency, and now you can view those reports and some other materials on our web site. They provide a fascinating look at the origins of our organization and the challenges faced in getting it started. Please visit [www.epilepsy-uny.org](http://www.epilepsy-uny.org)

Working with Pat were five others who devoted time and energy to starting the organization: medical advisor Maurice Charlton, M.D., Eugene Borgna (the agency's first president), Susan Nightingale, Pat Edgerton, and Betty Viken, who served as secretary and then as a president and board member. Betty recalls those early days: "We met in our homes until we found a storefront office on Alexander Street. One of our first tasks was to educate people about what epilepsy is and isn't, so we made presentations to the police departments and their training academy, the fire departments, and the schools. In 1979, we hired a nurse, Jean Streppa, as our first executive director and she was ably assisted by Janet Lindsay. As our name got out and people started calling us for help, the agency just grew and grew. In 2007, I'm just amazed at how large it has grown and all that it has accomplished."

PS Congratulations this year are also in order to our Syracuse office for celebrating ten years of affiliation with the Epilepsy Foundation.



**Right: Epilepsy Foundation board president Stuart Gebell, Syracuse regional director Deb Lewis, and president and CEO David Milliman prepare to cut the cake celebrating the Syracuse office's 10-year affiliation.**

**Far Right: Community relations associate Debbie Baker, national Foundation president-elect Joyce Bender, and David Milliman join in Syracuse's celebration event.**



### Mission

Remove the stigma of epilepsy and help people with epilepsy and related disabilities reach their potential.

### Vision

First-in-mind for innovative programs, fast response and high-quality services for people with epilepsy and related disabilities.



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