

Editorial

Living Well II—A Review of Progress since 2003

As readers of this Journal know all too well, epilepsy has been misunderstood, mistreated, and misinterpreted since the dawn of recorded history. As recently as the early part of the 20th century, epilepsy was theorized to be a trait shared by the most depraved criminals and the greatest geniuses. Those theories, though deeply flawed by current reasoning, added to the ages-old social burden of living with epilepsy. As we all know, that burden has varied with time, but still retains its serious effects on employment, marriage, physical function, social interaction, general well-being and mental health.

Three years ago, the burden of epilepsy at the beginning of the 21st century was outlined at the historic Living Well with Epilepsy II Conference in Baltimore, MD. It is a different burden from that of an earlier age, but it is still a major issue for people with epilepsy, and for the first time, quantitative studies are demonstrating just how much it can affect daily life. What was even more significant about Living Well II was the commitment and energy that the families, the individuals with epilepsy, and their friends in the caring professions brought to the gathering, their determination to state the issues clearly and to bring about change.

Today, the progress being made through work being conducted by the Centers for Disease Control and Prevention (CDC), the Epilepsy Foundation, the American Epilepsy Society, the Health Resources Services Administration (HRSA), the National Association of Epilepsy Centers, and the National Institute of Neurological Disorders and Stroke (NINDS), as outlined in the following Special Report is clearly evident. It's encouraging to see these organizations working together in a Living Well Task Force to implement the recommendations outlined in the Living Well II conference report. This kind of collaboration is necessary if we are to make a positive difference in the lives of people with epilepsy and their families and if we are ever to give epilepsy a higher profile in public health.

As this report shows, many good things are happening. We know more than ever before about new treatment options, and we are striving to reduce the time to diagnosis and appropriate care. We are educating physicians and consumers about conditions like mood disorders and memory problems that severely impact some people with epilepsy, and to address these co-morbidities as early as possible. We are striving to eliminate the stigma and the negative social implications faced by students with epilepsy in our school systems. Research to address quality of life issues and new therapies is underway.

The stigma associated with epilepsy still exists. It is a tough foe and it has to be confronted again and again. Public awareness and community education programs being conducted by the epilepsy community have helped to increase awareness and understanding of this condition, as well as dispel some of the myths. Eliminating the stigma associated with epilepsy is a national priority for each organization of the Living Well II Task Force. The continued collaboration between all the agencies who came together in Baltimore and who are continuing to work on all the issues associated with epilepsy is one of the best ways for us to achieve meaningful results—on stigma and all the other burdens that shadow people's lives. Much work remains to be done, but together, we believe we will meet the challenge.

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