



*I may not speak, but I have much to say.*

March 2009

Dear Friend,

Hope and change. Two words that we have heard echoed loudly across this country throughout the months and weeks leading up to our most recent elections. They are, however, more than just words. For you, our family and friend, they are what inspire and motivate us to be more, to do more, to continue on and face the challenges that lie before all of us. What is the change that you can affect? What is your hope?

As friends and family members of individuals with Angelman Syndrome our lives have not been easy; neither have we been willing to settle for less than what our loved ones need to attain her or his fullest potential. We have been the agents of change in our loved ones lives and we will continue to do so. Throughout the Angelman continuum there is work to be done. Earlier diagnoses, more effective therapeutic interventions, advances and bolder initiatives in basic scientific research and clinical trials; life changing skill acquisition and independent living. Our hope is that we will see significant changes and advancements in all these areas, not just in our loved ones' lifetimes, but also at an accelerated rate. We are the agents of change for our loved ones. We are their hope.

**Saturday, May 16, 2009 the ASF National Walk-A-Thon will be held in 24 cities across the US.** Today your participation is more critical than ever. Currently, more individuals are being correctly diagnosed with Angelman Syndrome and they, and their families, need our help and support. You may be a part of one of these families or their support network. Participation in the ASF National Walk-A-Thon not only supports others, it supports you and your family as well. Each local walk site offers its own unique opportunities to meet and network with others who know and understand all of the challenges and joys faced on a daily basis in caring for an individual with Angelman Syndrome. This is an opportunity for you, your family and your support network to strengthen relationships and supports for your loved one and your family.

Now, more than ever, there is a tremendous interest throughout the scientific and research communities to find the answers we all are so desperately seeking. What causes Angelman Syndrome? How can we effectively treat seizures, behaviors and other concerns in individuals with Angelman Syndrome? When will we cure Angelman Syndrome? The reality is that Angelman-related research cannot accelerate until *significant* funding is made available for both basic scientific and clinical research.

The Angelman Syndrome Foundation is the single-largest funding agency for Angelman-specific research and the ASF National Walk-A-Thon is the ASF's premier fundraising event. Proceeds from the ASF National Walk-A-Thon support critical Angelman-focused research; educational offerings, such as the 2009 ASF Scientific Symposium and Biennial Conference and quarterly regional educational workshops. Proceeds also help make available vital information for ASF members and other families, care providers and professionals who care and provide for their special individual with Angelman Syndrome.

The Angelman Syndrome Foundation is ardently committed to improving the lives of individuals with Angelman Syndrome and their families. What does the future hold for our loved ones? Come, experience the camaraderie, joy and support at the 2009 ASF National Walk-A-Thon. Become a significant force in changing the lives of individuals with Angelman Syndrome and your own life. Your participation in the 2009 ASF National Walk-A-Thon will help us reach out to those who need our help. I know I can count on your help. As President Obama said in his inaugural speech *"What is required of us now is a new era of responsibility . . . that we have duties to ourselves [and others] that we do not grudgingly accept but rather seize gladly, firm in the knowledge that there is nothing so satisfying to the spirit, so defining of our character, than giving our all to a difficult task."*

**Registration** for the ASF National Walk-A-Thon **is now open**. Simply visit the ASF website [www.angelman.org](http://www.angelman.org) to complete your registration. Once you have registered to walk at one of our 24 walk sites on Saturday, May 16 you will be directed to set up your own personal fundraising page. Personal fundraising pages are safe, secure and the most efficient way to help others support you in your fundraising and awareness efforts. Once you have registered and set up your personal fundraising page a walk fundraising packet will be sent to you with information specific to your local walk site. If there is not a walk site near you, don't despair! You can register as a virtual walker. Actual or virtual—no matter which walk you choose, you will help change many lives for the better.

With grateful appreciation for your help and participation,

*Eileen Braun*

Eileen Braun  
Executive Director, Mom to Kaitlin (18, Deletion Positive)

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