

# Congress of the United States

Washington, DC 20515

## Reception and Film Screening Canavan Disease

June 18, 2004

Dear Colleague:

Earlier this month you should have received an invitation from Jacob's Cure, a national organization dedicated to raising awareness of Canavan disease, to a special reception for members of Congress, staff, and advocates. The evening will feature a screening of "As Daylight Breaks," a film that chronicles Jacob Sontag's life with Canavan disease. We hope that you will join us for this important event.

Few are familiar with this "orphan" genetic disorder, though it has debilitating, fatal consequences for young patients. Striking in infancy, Canavan renders children unable to crawl, walk, sit, talk or sometimes swallow. These children will never reach the same milestones as their peers. Parents who learn their children have this disease must also face the fact that there is no standard treatment and worse, there is no cure.

Since her son's diagnosis, Jordana Holovach has been working tirelessly to defeat this disease – establishing Jacob's Cure, supporting efforts to double the National Institutes of Health's budget, and raising awareness by talking to the media and legislators. Her efforts have helped to make a difference -- the Canavan gene was located and new, focused research on this disease has begun to yield potential preliminary treatments. Furthermore, Canavan research has influenced research on several other diseases such as Tay-Sachs, Multiple Sclerosis, ALS (Lou Gehrig's) and Parkinson's disease. For example, the Canavan project was recently cited as the basis of the Parkinson's gene-therapy trial.

However, because Canavan disease is an "orphan" disease, it is a daily struggle to establish initiatives directed towards Canavan disease and entice researchers into the field. Yet, the need to find a cure so clearly remains. Please join us to hear Jacob's story and to meet Canavan families, including Jacob himself.

**Wednesday, June 23, 2004**

**Library of Congress, Thomas Jefferson Building (10 First St. S.E.)**

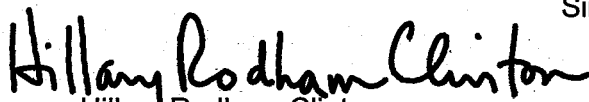
**6:00 p.m. Reception, Whittall Pavilion**

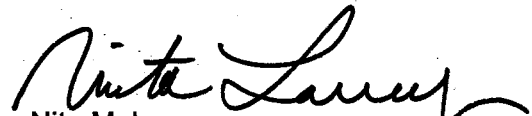
**6:00 – 6:30 p.m. Remarks by Senator Hillary Rodham Clinton & Congresswoman Nita Lowey**

**6:30 p.m. Film screening, Coolidge Auditorium**

To RSVP, contact Jordana Holovach, Jacob's Cure, at 914-673-2796.

Sincerely,

  
Hillary Rodham Clinton  
United States Senator

  
Nita M. Lowey  
Member of Congress