CHELSEA’S HOPE

BY LINDA AND HOWARD GERBER

Imagine an active and vivacious teenage girl who is as healthy and vital as her classmates. Just imagine her being an avid soccer player and dancer with a dynamic social life, one who possesses a cheerful demeanor and a vibrant smile that could light up a room. And imagine that this girl, at the age of 14, suffers her first grand mal seizure; an ominous inception of what would later be diagnosed as an exceptionally debilitating and progressive disease, changing her life forever. Now imagine that this beautiful child is *your* daughter.

She is *our* daughter, Chelsea Gerber, a beautiful, smiling, sweet and loving, 18-year old Danville girl who is dying. Chelsea has Lafora disease, an exceedingly rare but terribly debilitating form of epilepsy whose victims number in the hundreds. This genetic seizure disorder presents itself in uncontrollable shakes (myoclonus), horrible seizures, and tremendous loss of cognitive ability. It typically takes its victims within ten years of onset. As if such an affliction were not enough, Lafora disease cannot be controlled with medications. *There is no cure.*

Lafora has taken so much from Chelsea. Today, four years from her first seizure, our daughter is unable to walk without assistance and requires the aid of a wheelchair to go from place to place. Once a bubbly and talkative chatterbox, she rarely speaks. She seldom eats due to her inability to swallow and receives nourishment through a feeding tube. Chelsea, who was modest and proud, requires round-the-clock care and assistance as she no longer has the autonomy to care for her personal needs. What Lafora has *not* taken from Chelsea is her pure and radiant smile. What Lafora will *not* take away from us, her family and friends…is *hope.*

Out of desperation, we began a foundation called Chelsea's Hope-Lafora Children Research Fund. Lafora, because of its rare disease classification, is most often misdiagnosed, receives little to no government funding, and has only a few medical experts in the world. With some diligent and thorough research (and perhaps a miracle or two), we connected with Dr. Antonio Delgado-Escueta, the world's foremost Lafora expert, doing research at the University of California at Los Angeles (UCLA).

Chelsea's Hope was born with love and determination to make a difference for the children and their families who have been diagnosed with Lafora. With the help of leading researchers, we have been able to provide a vital link for both families and neurologists to gain important medical information as well as educate the rest of the world about this painful disease. The families of these children had no place to go and no community to lean on. In addition to dealing with the horrors of this disease, they were isolated in their fears and concerns for their children. With Chelsea's Hope, we have created a home and a network for all families who live with this horrific disease.

Though times are tough all over the world, those of us who live in the Bay Area know that we are privileged. We live in an area where there are abundant resources along with superb hospitals and service providers. Over the past several years, Danville and the Tri-Valley area have joined hands to celebrate with Captain

"Sully" Sullenberger when he landed the plane in the Hudson and saved so many lives. We collectively mourned when the Pack family lost their beautiful children because of a drunk driver. Today we ask that the wonderful spirit of our Danville community help us wipe out a disease.

We are desperate to raise funds so that no other child has to lose so much, no other family has to watch their beloved child struggle to utter a word, and no other researcher loses their job due to lack of funds. Chelsea and all of the other children around the world suffering from Lafora disease deserve to have more studies conducted to curtail their suffering. More research will lead to fewer children being born with this fatal diagnosis.

Please visit us at www.ChelseasHope.org and donate what you can; we sincerely appreciate any and every donation. All contributions go directly to the Lafora Children Research Fund at UCLA and are tax deductible. See what you can do to help and make a positive difference in the lives of these afflicted children.

"Alone we can do so little: together we can do so much"...Helen Keller

Chelsea Gerber, her father, Howard, mother, Linda and brother Collin.

Photos p54 courtesy Cheryl Bigman Photography

Researchers for Lafora Disease are currently focused on developing treatment protocols and studies, and funds are urgently needed to support these efforts if we are to accomplish a cure for Lafora Disease.

All donations to the Lafora Children Research Fund are tax deductible.

Chelsea's Hope, supporting UCLA Lafora research, is hosting its first fundraiser to be held on May 17, 2009 at Forli Restaurant in Alamo from 1-4. For more about attending this event, please refer to our website.

We'd love to have you join us!

Please visit our website, read their stories, learn about Lafora & find out how you can help at www.chelseashope.org

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