

Application for Home Modification Funds

Who We Are

Name and ages of all family members:

- [names and ages listed here]

We currently live at [address removed]. We moved to [town name] in 2007 just before Ivan's second birthday. We are originally from the Big Island of Hawai'i, but we were having a lot of difficulty getting the services and medical treatments that Ivan needed there so we started researching other areas. Esoos and I had both attended college in Boston so we had friends here, Children's Hospital Boston is the top rated pediatric hospital in the country and Perkins School for the Blind is the best school for visually impaired students in the world. Moving was a fairly easy decision, though it was hard to leave our families behind.

We found a very nice two-story house to rent on [street name removed]. Our landlords lived across the street and our neighbors were all very supportive and helpful right from the start. When our landlord offered us the opportunity to buy the house we had been renting for five years we jumped at the opportunity. We are very happy in this house and in this neighborhood. We purchased the house with the knowledge that we would soon have to modify the house to accommodate Ivan, who is getting bigger every day. We do plan to live in this house and stay in this neighborhood long term.

Ivan's Disabilities

Ivan is seven years old and weighs about 50 pounds. He is totally blind, has a seizure disorder and global developmental and intellectual delays. He is non-verbal, non-ambulatory and has extremely low muscle tone (hypotonia). Ivan is diagnosed with Joubert Syndrome, Landau-Kleffner Syndrome, Leber's Congenital Amaurosis, Osteoporosis and Oropharyngeal Dysphagia.

Joubert Syndrome is a neurological disorder resulting in a missing or hypoplastic cerebellar vermis, the part of the brain responsible for muscle tone, coordination and balance. Ivan cannot walk unassisted and has difficulty with motor planning and dexterity. He also has very low muscle tone and has difficulty standing or sitting up on his own for long periods of time (he tires easily). He must also have his hips and spine monitored closely for proper development because children with low tone who do not walk can develop hip and spine problems. Ivan is

currently diagnosed with osteoporosis as well, so we encourage him to stand and move as much as possible, but this is all done with assistance.

Landau-Kleffner Syndrome is a seizure disorder characterized by seizure activity in the language center of the brain. Ivan cannot speak verbally or communicate through sign language. He does understand some of what is said to him, but his receptive language is also impacted by the disorder. Mostly he communicates by smiling, laughing or fussing. His emotions are actually pretty easy to read.

Leber's Congenital Amaurosis is a disorder affecting the retina which causes severe retinal degeneration from birth. Some children with LCA can see light or shadows, but Ivan has been completely blind since birth.

Oropharyngeal Dysphagia is a swallowing disorder that in Ivan's case is most likely related to his low tone and sensory issues. Ivan has difficulty understanding what kind of food or liquid is in his mouth and often chokes or aspirates while eating or drinking. He has to be fed carefully and can only drink thickened liquids. Ivan loves to eat and actually enjoys a wide range of foods, but he cannot feed himself and all of his foods need to be cut up really small and fed to him very slowly. Feeding Ivan dinner, for example, usually takes about 90 minutes.

Ivan does receive PCA services through his insurance (22.75 hours a week) to help us at home. He also attends Perkins School for the Blind five days a week as a day student (he is not residential) where he receives services from a Teacher of the Visually Impaired as well as all his therapies (Occupational Therapy, Physical Therapy, Speech Therapy, Music Therapy, Orientation & Mobility, Art Therapy and Adapted Physical Education). Ivan is placed at Perkins through an IEP with outside placement with our School District. His tuition is paid for by the town, but there are no additional costs. Ivan does also receive extra physical therapy and aquatherapy at Franciscan Hospital, but this is covered by his insurance.

Ivan's social worker and case manager at Perkins School for the Blind:

[name and address removed]

Ivan's School District case manager and out of district coordinator:

[name and address removed]

Ivan's pediatrician:

[name and address removed]

Our Project

It is very important to us that Ivan continue to live at home with us for as long as possible. Ivan has a lot of challenges and we feel that only his parents can truly address all of his needs, including his social and emotional needs.

As Ivan is getting bigger, it's becoming more and more evident that he needs to be able to live on the first floor of our house. Since the only bathroom in our home is on the second floor, we need to build an accessible bathroom for him on the first floor as well as a wheelchair ramp so that he can get into the house. Building the bathroom will also allow us to create a new door into the dining room that will accommodate the size of a wheelchair.

Our plan is to build an "L" shaped ramp that will start at the sidewalk in front of our house and come in on the left side of our front porch. We will need to put in a new storm door on that side and also build a higher floor for the front porch so that Ivan's chair can wheel directly into our front door (which is currently up on a 6 inch threshold).

We will move Ivan's bedroom downstairs (no modifications necessary to do that) and build an addition off the left side of the house to encompass a small changing room and large accessible bathroom. The changing room will have a changing table and some storage for Ivan's clothes (at wheelchair level). The bathroom will have space for a wheelchair, an open sink, grab bars around the toilet, and an accessible bath tub. The bathroom will also have a large door that will enter into the dining room so that Ivan's wheelchair can be wheeled into the dining room.

Because the bathroom will have to be built as an extension, we are also going to have to dig a foundation and heat the new bathroom.

The full cost for the project is [cost removed]. Break down of cost is as follows:

Material: [cost removed]

Labor: [cost removed]

Funding

We have applied for (and anticipate receiving) [grant and amount removed].

We have also applied for (and have been approved) [grant and amount removed].

We have also applied for (and our application is pending) [grant and amount removed].

We are waiting to hear back from [grant and amount removed].

Permissions

We give permission to [organization name] to contact Ivan's school and doctor to gain additional information.

We will allow [organization name] to use our family's story for potential fundraising sources.