

Dear Long Island Home Builders Care, Inc

Since the diagnosis of both of our young boys we continue to do everything in our power to help our son's live happy, healthy and productive lives. Nicholas, 5, and Tyler, 4, are both afflicted with a rare genetic disease called Spinal Muscular Atrophy, better known as SMA II. This debilitating disease affects all their voluntary muscle movements throughout their entire body. It prevents them from crawling, standing, walking and eventually even swallowing. It also affects the muscles in the neck, control and movement of the head, as well as respiratory function. SMA is the # 1 cause of death in infants under the age of 2. This disease is unpredictable and a common cold could cause life threatening complications in just hours. This past year has been extremely difficult for our boys. Tyler was hospitalized several times with RSV, a collapsed lung and pneumonia as a result of an upper respiratory infection. For most children this would have cleared up with antibiotics, but for Tyler this turned into a devastating experience, resulting in very intrusive therapies every 2 hour and several lengthy hospital stays. Nicholas was also hospitalized for RSV, collapsed lung & Pneumonia but fortunately recovered with less severe complications. This disease also causes our children to have extremely brittle bones, increasing the chance of injury and fractures. Last year Nicholas had a broken leg and Tyler had a fractured shoulder. It is extremely important that they be handled delicately to prevent these types of injuries.

Nicholas and Tyler will not only require a lifetime of support from a team of medical professionals, but also intense therapies on a daily basis to survive and hopefully thrive. SMA is a progressive disease, so each and every day their little bodies are slowly being robbed of another ability.

Furthermore, they require a great deal of costly medical equipment that is not fully covered by insurance, if even covered at all. Unfortunately, the prognosis for the boys is that they will spend their lifetime in power chairs as their only means of mobility. Activities that seem simple for some, like a doctor's visit, is incredibly challenging for our family. It is imperative that we have a wheelchair accessible van that accommodates both boys, and us. At this time the boys are not able to be independent outside of our home because we cannot transport their chairs, which means they need to be pushed in adaptive strollers. They understand that without their chairs they don't have their freedom and it is upsetting for them and is also much more difficult for us, as parents. In addition to the challenges with transportation at this time, we are still working towards a handicap accessible home. These modifications will allow for our two boys to safely and independently navigate their own environment, the place they call home. As you can imagine the tremendously high costs of such renovations have made our goals seem unattainable. We would appreciate any help that could come our way. Here is a list of the goals we are trying to achieve in order to give Nicholas & Tyler the best quality of life possible. We thank you for taking the time to even consider us and hopefully have the opportunity of working with you.

- **Handicap Accessible Van** - The expense of a vehicle that can support two power chairs is very high. The types of vehicles that can be used is limited and the price is in the range of \$80K and \$90K.
- **Elevator** – An Elevator needs to be installed to allow the boys access to the basement. My parents will be occupying the basement, however, we would like the boys to have access as they like to spend time with my parents in addition to the fact that they will most likely be occupying that space in the future. This is the only way to access the basement living space from inside the house.
- **Kitchen Floor and Back Door** - The back door in the kitchen sits on wood that is rotting and the floor is damaged in and around the back door as well. Much of the kitchen floor is unsafe for the boys to travel on with their power chairs.
- **Kitchen** - The kitchen needs to be more accessible and safe for the boys
- **Widen Door Ways** – The door ways to each bedroom is currently too small for the power chairs to fit easily. The doors become a little more damaged each day with the boys trying to get in and out of their bedrooms.
- **Side Entrance** – The side entrance resides in what is now the apartment kitchen. The apartment will become our master bedroom, bathroom and laundry room. The bathroom and kitchen is 2 steps lower than the rest of the house. We planned on making everything level for accessibility. My parents are currently in the apartment but will be moving downstairs as soon as the basement modifications are complete.
- **Potty Chair** – We have been trying to get a potty chair for the boys and even increased our insurance policy hoping it would be covered. We have increased our policy cost from \$110 per week to \$265 per week and the chair was still denied. We plan on paying for the chair out of pocket as both boys should be out of diapers at their ages of 4 and 5.
- **Attic Stairs** - The attic stairs are currently in the small hallway that will become part of the bathroom. The bathroom project has begun and once complete, we will no longer have access to the attic. The stairs must be moved to the main hallway.
- **Retrofit Apartment to Master Bedroom, Bath and Laundry Room** - As I mentioned, when my parents move to the basement, we will have to build the master bedroom, bathroom and laundry room.

There is much more detail that we can provide and we would be happy to discuss any or all of the items listed above. Any of these items removed from the list would be a huge burden lifted and a step in the right direction. It is extremely difficult to express the feeling of knowing what your children need without the means to provide it. In the beginning we had a hard time asking for help, but when you see the struggle of two of the most important things in the world to you, all of a sudden it no longer seems so difficult. We truly appreciate your consideration and thank you for all of your support and prayers.

Sincerely,
 Nick & ToniAnn Accardi