

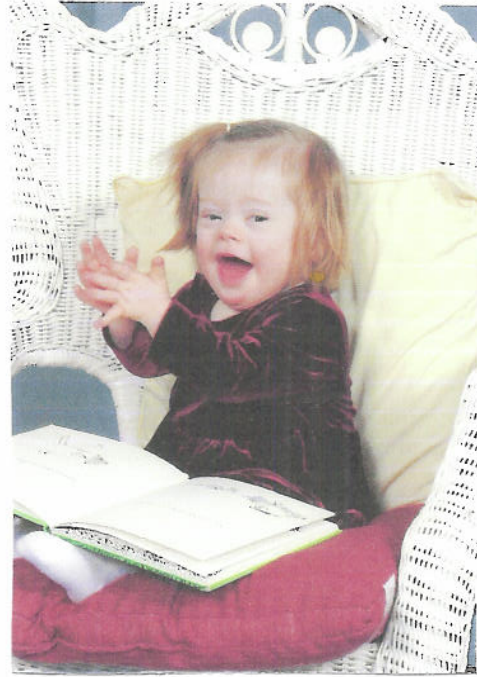
*Grace Ellen Ames*



*all about me...*

Thank you for allowing us to introduce you to our daughter, Grace. We hope to give you some background information in order to assist you in her evaluation process.

Grace is 2 ½ years old. She has already learned to walk. She says some words and knows many more in sign language. She likes to listen to music and is starting to sing along. She is outgoing and affectionate. Grace quickly touches the hearts of whomever she meets. As her parents, we want to do ensure that Grace is given every opportunity to reach her full potential. We look forward to working together with you as we begin the next step toward building a successful educational foundation for her.



## Family Life

Grace is the youngest of seven children. Her home is very busy and often very loud. Grace likes to be in on the action with her brothers and sisters. She enjoys rough play and isn't bothered by loud noises or crowds. She is very friendly and is developing a sense of humor. She is quite adaptable and is able to tune out the noise and activity to concentrate on the task at hand.

Our older children all participate in Grace's therapy to some degree, whether it is sitting in on sessions or just learning helpful ways to play with her. We believe that Grace benefits from her large family. She is flexible and has very few sensory issues.



## Health History

Grace was born on June 23, 2005. She had been diagnosed prenatally with a complete AV Canal heart defect. The middle of her heart had not developed properly. Open heart surgery would be required to patch two holes in her heart and to create two separate valves where she only had one. At least half of children with this defect have Down Syndrome, so we were not surprised when she received this diagnosis at birth.

Grace spent only a few extra days in the NICU. She was slightly jaundiced and her blood oxygenation levels were a bit low. During this time we learned to deal with some of the difficulties babies with Down Syndrome have with their feeding.

Babies with the AV Canal defect are expected to go into heart failure and in Grace's case, this happened quite rapidly. She was hospitalized two times in her first six weeks of life – once to begin managing her heart failure with medication and once because she had aspirated and turned blue.

On September 12, 2005, Grace had her heart repaired at Children's Hospital of Philadelphia by Dr. Thomas Spray. Four days after open heart surgery, Grace was discharged. The immediate improvement in her health made us feel like we were bringing home a brand new baby. We now follow up once a year with her cardiologist, Dr. Christine Donnelly, at Morristown Memorial Hospital. A slight protrusion exists at the base of Grace's breastbone but this is not cause for concern.

When Grace was ten months old she had tubes inserted in her ears. This was necessary because she had had five ear infections and her speech was delayed by fluid in her ears. We saw an immediate improvement. She began vocalizing the next day and had no more ear infections. The tubes were removed last fall and she has only had two infections since

then. We closely monitor her ears for fluid and infections since we know how quickly these affect her speech development.

Grace also sees a pediatric ophthalmologist, Dr. Anthony Caputo. She is far sighted and should wear glasses at least for her therapies. She has not been very cooperative about wearing them at any other times, but we hope that this is because she has nearly outgrown them. She is due to see Dr. Caputo in late March and should be fitted for new glasses at that time.

## **Therapies**

Grace started receiving early intervention services through the state in our home at one month old. She started with physical therapy. She began receiving speech therapy at three months. Occupational therapy was added when she was one. She has each of these for one hour a week.

Since turning one, Grace has participated in the early intervention program offered at Stepping Stones in Livingston. Stepping Stones is a center based program sponsored by the ARC of Essex County, providing early intervention, preschool and primary grade education primarily to children with Down Syndrome. At Stepping Stones, Grace benefits from small group therapy sessions for two hours, twice a week.

## **Physical Therapy**

Grace's physical progress was very slow at first. She finally sat up just before her first birthday. For a very long time she didn't even know she had feet. But last spring, Grace really began to progress physically. She pulled up to standing before she turned two. She started walking at two years and four months of age and now walks confidently on level surfaces. She will fall easily if bumped and is not very good at stepping over things, causing her to trip and fall. She can climb up onto and off of chairs. She can crawl up stairs, and go back down on her belly. She can throw a ball.

With her therapists, Grace is working on walking up the stairs, but right now this requires much assistance. She is learning to use a ride-on toy. Other goals are jumping, kicking a ball and running.

## Occupational Therapy

When Grace finally started walking, it became a challenge for her occupational therapists to treat her. She wanted to be on the move. But recently Grace's attention span has grown and her fine motor skills are improving. She will attend to a task for 5-10 minutes. Her posture has improved, but we are still working on her lateral weight shift. Her tripod grasp is emerging. Scribbling in lines and circles is emerging. She is starting to match colors. Grace likes in & out play and cause & effect toys.

Grace's early self-help skills are delayed. She will help a little to dress herself with verbal cues. She can eat with a spoon and is starting to poke with a fork. She displays no awareness as far as being ready to potty train.



## Speech Therapy

Grace can say many words and can sign more. She labels objects spontaneously. Putting two words together is emerging. Her receptive language is very good. She can follow directions but does much better when cued by signs.

Sign language has been key to Grace's language development. She was able to communicate her needs through sign long before she spoke a single word. Now, because she loves her *Signing Time* videos, she learns a sign and eventually the spoken word follows. These videos have been very helpful since Grace such a visual learner.

Grace really enjoys pretend play. She plays with toy food. She pretends to feed her doll. She can point to the parts of her body.

Grace's processing is a bit delayed. She does not always answer questions, or might take a little extra time. It is important to have her full attention when speaking to her. We are working on modeling appropriate responses to questions.

One area of **great** concern is Grace's self-feeding. When left to herself she stuffs her mouth. She has stuffed to the point of blocking her airway on two occasions. One time we even called the rescue squad, although we were able to clear the food before they arrived. When spoon-feeding or using a fork, she has some ability to regulate. But always, especially when finger feeding, she must be very closely monitored for her own safety.

Before we took Grace home for the first time, a wise doctor told us he would not even try to predict how far Grace would go because he has repeatedly seen children with Down Syndrome far exceed society's expectations for them. We have high aspirations for Grace and see her early education as the key to her future success. We realize her road will be more challenging than most, but we will gladly travel it with her, supporting her in any way we can.

