

## Annunciation Cathedral

Annunciation Cathedral is located at 245 Valencia St., in the Mission District of San Francisco. Annunciation Cathedral serves over 1,000 families, primarily of Greek decent. The Cathedral serves as the Cathedral Church for the Metropolis of San Francisco and the headquarters for many fraternal and national organizations.

**415-864-8000**

**[www.annunciation.org](http://www.annunciation.org)**

The Kallas family are members of the Cathedral. With your generous gift of love, together we can help Dr. Tomatsu to a clinical trial and a treatment for our beloved children!



Ariana, Bertha, Andrew, and George Kallas

**[www.arianascure.com](http://www.arianascure.com)**

**[www.morquio.com](http://www.morquio.com)**

## A Gift of Love for **Ariana**



Only through research can we find a cure for Ariana and other children with a rare genetic disorder called:

**Morquio**

# Ariana's Story

My name is Bertha Kallas and I want to share with you the journey my husband George and I have been through in the last ten months. In April of 2006, we were told my daughter, Ariana, has a severe medical condition. Ever since that day, it has been an emotional rollercoaster of highs and lows and an endless stream of tears.

Our daughter, Ariana, was born on July 1, 2005. I remember the moment the doctors told us our baby was a girl...perfect! We already had a two year old son named Andrew and giving him the gift of a baby sister made our family complete. We knew Ariana was unique from the moment we laid eyes on her. Her beautiful fair skin and strawberry-blond hair was proof enough that she would always stand out from the rest. She's always had such a delicate sweetness to her, yet a very strong will and determination, which I now realize is God's way of preparing her for the many challenges she has still yet to meet.

Initially, Ariana developed normally and there was no indication of any serious medical problems. After a few months, we began to notice she wasn't hitting her developmental "milestones", but what concerned us the most was an odd bump forming on the low part of her back. I remember thinking it couldn't possibly be anything serious. How very wrong I was...

Our nightmare was confirmed on April 21, 2006, after a set of X-rays indicated a very severe problem with our baby's low spine and hips. Her doctor brought me back into his exam room and said to me, "Mom, are you ready to hear any kind of news?" I knew at that very moment that I had to emotionally brace myself for what I was about to hear. He said, "Your daughter has three deformed vertebrae in her low spine, her hips are abnormally shaped & I feel she may have a syndrome." Well, needless to say, the rest of the visit was a blur and I fought extremely hard to see and drive home through the endless flow of tears. My world had just crumbled into pieces and my heart ached like nothing I'd ever felt before.

After several months of what seemed like endless doctor appointments, MRI's, catscans, and lab tests, we finally received the results we had so long dreaded, but were eager to find out so we could finally move forward. Our baby was diagnosed with Morquio IV- Type A.

Ariana, our little songbird as we like to call her, has been such a blessing to us. I believe with all my heart that God has a purpose for her. Maybe it's to teach others about children with similar disabilities and to help open up their minds and hearts. Maybe it was to teach her mommy and daddy the meaning of strength. I can truly say she has brought out an inner strength in us that we never realized existed. When I begin to doubt and second guess myself, I always think of her. She never had a choice in life and has had to be strong since day one. She's our little angel and I thank God every day for giving her to us. Our lives will never be the same, but she has changed it for the better. This was just meant to be...she was meant to be. Our little gift from heaven.

God willing, with the help of family, friends, and the Annunciation Cathedral in San Francisco, we will be hosting fund raising events. This is in hopes of helping Dr. Tomatsu and his research. We know that treatment, if not a cure, is right around the corner. However, we also know that it takes all of the community to come together to help support this cause. It pleases us that 100% of the donated funds will go directly towards Dr. Tomatsu and his research.

We want to thank everyone for the love, support, and especially all the kind, encouraging words we have been receiving. It really means the world to us! I know we'll get through this very difficult time and eventually come out much stronger, especially our little Ariana Marie. She definitely has a long road ahead of her, but she also has the love and faith of the Lord and the support of her family and friends to help guide her through all the bumps and roadblocks along the way.

With all our love,  
George, Bertha, Andrew, and Ariana Kallas

## WHAT IS MORQUIO?

MPS IV, Morquio syndrome is one of the mucopolysaccharide diseases also known as MPS IV. It takes its name from Dr. Morquio, a pediatrician in Montevideo, Uruguay, who in 1929 described a family of four children affected by the condition. What causes Morquio disease? There is a continuous process in the body of replacing used materials and breaking them down for disposal. Children with Morquio disease are missing an enzyme which is essential in cutting up the mucopolysaccharide called keratan sulphate. The incompletely broken down mucopolysaccharides cannot be used in the proper development of bones and cartilage and remain stored in cells in the body causing progressive damage. Babies may show little sign of the disease but, as more and more cells become damaged, symptoms start to appear.

Physical growth slows and often stops around age 8. Skeletal abnormalities include a bell-shaped chest, a flattening or curvature of the spine, shortened long bones, and dysplasia of the hips, knees, ankles, and wrists. The bones that stabilize the connection between the head and neck can be malformed in these cases; a surgical procedure called spinal cervical bone fusion can be life-saving. Restricted breathing, joint stiffness, and heart disease are also common. Children with the more severe form of Morquio syndrome may not live beyond their twenties or thirties.

How is Morquio Disease inherited? It is estimated that one in every 25,000 babies born in the United States will have some form of the mucopolysaccharidoses. It is an autosomal recessive disorder, meaning that only individuals inheriting the defective gene from both parents are affected. When both people in a couple have the defective gene, each pregnancy carries with it a one in four chance that the child will be affected. The parents and siblings of an affected child may have no sign of the disorder.

Is there a cure? At present there is treatment for symptoms as they arise but no cure for the underlying disease.

## FUNDING FOR MORQUIO TYPE A RESEARCH

With hope, a wonderful miracle is just around the corner. Dr. Shunji Tomatsu, Associate Professor at The St. Louis University, MO is the Biochemist & Molecular Biologist researching Morquio Type A. has isolated and created the enzyme that will completely stop the progression of this terrible disease in young children. In fact, Dr. Tomatsu believes he is close to providing the necessary treatment that would completely eliminate the symptoms of this disease. However, he has reached a funding crunch that could prevent him from going into clinical trials with his enzyme replacement therapy.

This is why we are asking for your help.  
Please send your contribution to:

**Annunciation Cathedral  
245 Valencia Street,  
San Francisco, CA. 94103  
Non-profit ID# 942702215**

**Please state that your donation is for  
the "Ariana's Cure" fund for Morquio.**