



Photo by Erika Masterson

Families who receive grant money: do they belong to a Secret Society? by Anara Midgett

I've heard more than one parent of a Special Needs child talk about getting a grant for this or that over the years. When pressed for details, the answer is usually vague and along the lines of "our Social Worker told us about it." It wasn't just one person being mysterious. For some reason, people don't like to talk about how they got their grants or to even tell the name of the organization providing the funds. It felt like there was a super secret society of families who had received grant money.

Frustrated by the lack of details about how to find and apply for individual grants, I made one of my blog's first directories about sources of financial support for families with Special Needs children. I was updating this directory last summer

when I learned The M.O.R.G.A.N. Project was accepting small grant applications for 2010. I decided to bust into the secret society, apply for our first individual grant, and then share my experience. Did I mention I'm not very good at keeping secrets?

Robert and Kristen Malfara learned that their youngest son, Morgan, had Pelizeaus-Merzbacher Disease www.pmdfoundation.org (PMD) when he was still an infant. PMD is a rare and progressively debilitating neuromuscular disorder. The family was told that Morgan would not make it to his fourth birthday. Parent to parent support played a crucial role in the Malfara's life after Morgan was diagnosed. As their involvement in the Special Needs community grew,

they realized that their access to information, supplies, and resources was a blessing others did not share.

They founded the M.O.R.G.A.N. Project in 2001 with the mission of promoting awareness, supporting parents caring for their special-needs children, and of enhancing the quality of life for special families. The name honors Morgan and is an acronym for Making Opportunities Reality Granting Assistance Nationwide.

On a personal level, the Malfaras were also anticipating using the Project as a way to keep going after the doctor's prognosis for Morgan came true. Kristen told me, "I was terrified of what would happen when I no longer had him. The M.O.R.G.A.N. Project was going to be my lifeline after he was gone ... and here I am, nearly 10 years later and I have BOTH my babies! I never, ever, ever intended to be doing both at the same time. But God had another plan for me, and I like HIS plan better!"

One of the ways the M.O.R.G.A.N. Project offers support is by providing funds for items or services not covered by insurance or Medicaid. I made a list of upcoming needs that insurance will not cover: new eyeglasses, an adaptive car seat, and a step stool with handrails. These were all obtainable with a little planning and help from other resources. I decided to apply for something that was impossible without financial help. I wanted to go to the DownsEd International conference in Atlanta.

The majority of the two step application process is completed online. In step one, applicants complete a pre-application form to be qualified to apply for the real thing. I had to ask local support groups for financial assistance and the Down Syndrome Association of

Atlanta, as conference organizers, for reduced rates. The groups were great about meeting the Project's specific requirements for proving I had tried to get help before requesting funds.

There were a couple small essays to write about my daughter and our needs. Since I write about my daughter so much, describing what makes her precious and Special was easy. Explaining why I wanted financial support to go to a conference was a little more difficult. I feared that money spent educating me would take money away from families who needed serious medical support equipment. Going to the conference would help my daughter, but I knew I'd have fun in Atlanta. I had grant app guilt!

The M.O.R.G.A.N. Project recognizes the role information plays in parenting a Special Needs child. That's why providing gently used medical equipment and funding for equipment and services are not the only ways they help families. They have committed to maintaining a Special Needs resource library on their website. The Project's mission also addresses quality of life for families with Special Needs children.

The Malfaras are parents like us. They understand how important parent to parent support is for maintaining balance on this journey of loving a Special Needs child. Conferences are sources of more than the latest information. They provide fellowship and help build communities. They are also expensive. If a parent has to choose between spending money on their child's needs or attending a conference, the child will win. This

is why small grant funds can be used for conference expenses. I "mom-ed up", got over the guilt, and pressed on with the app process for my quality of life, as well as my sweet girl's future.

We qualified for step two – the actual application! Step two was even more Internet based than step one. There were more short online essays describing our needs and the request. Several forms had to be downloaded and signed. My daughter's pediatrician had to sign proof of disability and her teacher had to write a brief statement

Grants for 2011 will not begin until Spring. Follow M.O.R.G.A.N project on FB for updates and additional announcements. Used medical equipment is available year round. Donations needed for the 2011 small grant cycle. 100% of donated funds go to families of Special Needs children.

about why this grant was needed. One form had to be notarized. Our strong support team made completing this part of the app quicker and easier than expected.

The biggest challenge I faced in the application process was scanning the documentation so it could be uploaded to the online application form. As an Internet based writer, you'd think I could handle scanning six or so pages. I handled it like the computer whiz I am. I got help from my husband, a neighbor, and Staples.

The M.O.R.G.A.N. Project is staffed 100% by volunteers to ensure that 100% of donations go to the families they support. Volunteers can help if applicants

have difficulty with the application. Instructions were easy to follow and a list of FAQ's was provided. Overall, the application experience was not excessively stressful or time consuming. If you are considering applying during next year's grant cycle, budget plenty of time for getting statements and signatures.

I got the grant! I could not attend the conference for personal reasons, so was given a conference DVD with the request that I pay it forward. I plan to throw a viewing party with some local friends to begin the sharing and get the socializing I missed. After the party, the dvd will be donated to the Junior League Family Resource Center at the Monroe Carell Jr. Children's Hospital at Vanderbilt. It will become part of their lending library to be borrowed by parents, teachers, and groups throughout Middle Tennessee.

Was I disappointed that I wasn't going to stay in a hotel, make new friends, and enjoy a little "me time"? A little, at first, but my grant app guilt is wiped clean by the thought of the conference information becoming a community resource instead of our personal resource. The M.O.R.G.A.N. Project's vision is about supporting all families, not just ours. We're proud to pay that vision forward.

