
THE M.O.R.G.A.N. PROJECT

From the Desk of Kristen Malfara

My husband and I began The M.O.R.G.A.N. Project in 2001, incorporating and applying for our 501(c)(3) without any assistance. Since that time, we have had other parent/caregiver members join us as volunteers, but the lion's share of the work has been done by just the 2 of us. Over the years our goals for this organization have gradually changed, based solely on our own experiences over the past 10+ years of caring for our son, Morgan, who was diagnosed with an extremely rare neuromuscular disorder called Leukodystrophy at just 8 months old.

Our original vision has not changed; it has just evolved to accommodate the additional needs and obstacles we have faced as our son has gone from an infant to a grade-schooler. As time has gone on, we have come to realize that we are not super-parents, and cannot do this without the assistance of dedicated volunteers willing to share their own experiences, talents and time with us as advisors, committee members and fundraisers. We must find like-minded business, corporate and philanthropic organizations that are willing to make sizeable grants to our grass-roots organization in order to continue to provide the support programs that we have in place, as well as funding the future visions of The M.O.R.G.A.N. Project. Every step we have taken for The M.O.R.G.A.N. Project has meant time away from other areas of our life that need our attention ... namely our children, and ourselves. We are the target group outlined in our mission statement! As much as we would like to move mountains, we have learned that we are only capable of moving one little ant hill at a time, so we try to devote ourselves to the big picture, but concentrate on completing the small things to the best of our abilities while juggling the rest of our life commitments.

Shortly after Morgan was diagnosed, we were devastated to learn his prognosis. It was not until 10 long months after this rare diagnosis when we accidentally stumbled upon a support group based in Indianapolis that changed our lives so dramatically. We learned that the only experts regarding our son's issues were ourselves ... no one knows your child like you do, and our number 1 priority was to be his advocate. Through this wonderful support group we learned so much, and credit that group of parents with making the biggest difference in our lives! The doctors rely on medical data and text books that have information based on studies that are sometimes decades old, and often times are no longer reliable sources of information. Every little thing that we have learned on our journey as Morgan's caretakers has come from another parent that has "already been there, done that" and we are better parents/caregivers/advocates as a result. We have learned from experience that this can make all the difference in the world to other parents who follow in our footsteps, and through The M.O.R.G.A.N. Project we hope to help light the way.



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VISION FOR FUTURE SUPPORT PROGRAMS

BRIEF HISTORY

We are a small group of lifetime committed volunteers that are uniquely familiar with the needs of families that choose to care for their chronically ill children with special needs in the family home, despite the personal sacrifices, financial burdens, stresses to the rest of the family, and emotional rollercoaster involved in doing so. Our organization is still a grass-roots effort, started just 7 years ago by our co-founders, Robert & Kristen Malfara. Some of us involved in this organization have had to bury our children already, some of us are still caring for our children years later, and some of us are just starting this journey with our children. What we have in common is our need to acknowledge the gifts in our lives (our special kids) by giving back in some way to our community ... by trying to help others that come after us and discover that there is no "special-needs 101 manual" that comes with these children. We want to help other very special caregivers that make the choice to keep their kids and not give up on them or institutionalize them, by giving them the support and tools that they need to do so, that they will not find anywhere else.

PROJECT OVERVIEW

The M.O.R.G.A.N. Project would like to establish a facility to house programs, services, equipment and resources for the family caregivers who have dedicated themselves to providing lifetime care for their children with special health care needs and disabilities, and that have taken on the role of advocating for the myriad services needed to care for these precious children with various disorders, yet very similar disabling needs. Our organization (unlike many) is not disease-specific and has been lovingly created to support and assist families who are caring for their physically disabled child - regardless of what the underlying disease or disability is. This facility will be a 2000 square foot building with a computer research and resource lab, equipment and loaner supply area, arts and crafts room, adaptive gym, adaptive quiet room, wheelchair accessible & climate controlled indoor playground, office and storage space, and fully handicapped accessible bathroom off the reception area. The M.O.R.G.A.N. Project will provide a safe environment for parents to bring their children with special health care needs and physical disabilities for hands-on therapeutic, creative and fun activity and play. The M.O.R.G.A.N. Project will provide the special needs equipment for use in our facility, as well as on a loaner basis. The goal is to offer an alternative to outdoor inaccessible playgrounds, "McDonald's" or "Chucky-Cheese" type playgrounds, "Mommy & Me" toddler playgroups, libraries, and other similar places/support groups that are unfortunately not appropriate for the special-needs child.

Additionally, our computer lab and resource library will provide parent caregivers with the tools they need to locate information and services that would benefit their children, as well as the support and services that would benefit their own needs. The M.O.R.G.A.N. Project plans to offer caregiver and advocacy training, support group meetings and other seminars on the various issues related to caring for children with special needs, navigating the medical and emotional hurdles, finding financial assistance, caregiver support, legislative issues, etc.

The M.O.R.G.A.N. Project's adaptive playground would be available for individual use, playgroup meetings, birthday parties, etc. In addition to providing a facility to house these programs, The M.O.R.G.A.N. Project plans to produce a comprehensive guide and companion website for parents, to help them empower themselves when tackling the many hurdles facing them as they take on the enormous responsibility of being the caregiver for their child with special health care needs and disabilities. Our hope is to eventually expand this aspect of our project nationwide, and help as many families as we possibly can. This lack of support is certainly not just a local problem; parents all over the country have taken on the burdensome privilege of becoming their child's caregiver, without any substantial support programs or services.



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PURPOSE & GOALS

The M.O.R.G.A.N. Project strives to develop a strong sense of self-worth within the caregiver families in the disability community, and therefore help them to help their children with special-needs without the normal associated feelings of isolation and overwhelming stress. There is a critical need to provide these services and programs for special-needs children and their caregivers in our South Brevard community, not to mention nationwide. Historically, many of these families have struggled with the increased risks and consequences of caring for a child with a life-threatening illness and/or disabling disorder in an area that is severely lacking in support facilities and services. Unfortunately, caregivers of disabled children have been relegated to being part of a "secret club" as a result of this lack of community support. Although making the dedicated choice to care for a chronically ill child with physical disabilities in the family home demonstrates the love and commitment of these very special parents and can be a very rewarding personal experience, the isolation often felt can be devastating.

Caregivers often learn through trial and error the best ways to help an impaired child maintain routines for eating, hygiene and other activities at home. Special training in the use of adaptive equipment and managing difficult behaviors may be needed. Trodding through the bureaucracy of applying for services can be overwhelming. Usually, a parent feels isolated and alone, and that no one else could possibly understand what their daily lives now entail. The consequences for a child with special health care needs and physical disabilities are extensive, and often times unexpected:

COGNITIVE DEFICITS: include shortened attention span, short-term memory problems, judgment deficits, inability to understand abstract concepts, loss of sense of time and space, decreased awareness of self and others, and an inability to accept more than 1 or 2-step commands at the same time.

MOTOR DEFICITS: include paralysis, poor balance, lower endurance, reduction in the ability to plan motor movements, delays in initiation, tremors, swallowing problems and poor coordination.

PERCEPTUAL DEFICITS: mean possible changes in hearing, vision, taste, smell and touch, loss of sensation of body parts, and difficulty understanding where limbs are in relation to the body.

SPEECH DEFICITS: include speech that is not clear as a result of poor control of the lips, tongue, teeth and other speech muscles, and poor breathing patterns.

LANGUAGE DEFICITS: difficulty expressing thoughts and understanding others, problems identifying objects and their functions, problems with reading, writing, pragmatic language, decreased vocabulary, and ability to work with numbers.

SOCIAL DIFFICULTIES: impaired social capacity resulting in self-centered behaviors, brain injury can result in difficulties making and keeping friends, as well as understanding and responding to the nuances of social interaction.

REGULATORY DISTURBANCES: include fatigue, changes in sleep patterns, not sleeping at all, dizziness, headache, and loss of bowel and bladder control.

PERSONALITY CHANGES: include apathy, decreased motivation, emotional liability, irritability or depression, temper flare-ups, aggression, cursing, lowered frustration tolerance and inappropriate sexual behavior.



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WHY THIS IS SO IMPORTANT

More often than not, the services and programs that would benefit the unique needs of these children with special health care needs and disabilities are inadequate at best, non-existent at worse. These children need daily physical, occupational and speech-language therapy in order to thrive, and more importantly, survive. The special-needs equipment that is needed to achieve this are numerous, expensive, and often times large and cumbersome. Most insurances and Medicaid will provide minimal therapy services (twice a week for 30 minutes) and mobility equipment (wheelchairs) but rarely will they provide for the services and equipment that would make the task of caring for these special-needs kids easier on the parent that is their primary caretaker. There are NO reimbursements for travel and associated costs for attending a medical conference or support group meeting. Many families do not have a home that is handicapped accessible, let alone have enough room to store all the equipment that would offer their child the maximum benefit. Parents spend most of their time providing hands-on care to their child with special health care needs, in order to supplement the minimal therapies they receive. Additionally, caregivers risk injury to themselves and their child while trying to "make do" without the proper safety equipment to lift, transition and transport their child.

More public awareness is needed to draw attention to caregivers needs. Children with chronic illness and disabilities need a broad array of information and services over a prolonged period of time. So do their family caregivers. Although caregiving and long-term care command attention in state legislatures and caregiver support programs play an important role in the everyday lives of these families, information about state-supported programs for caregivers and their disabled children is limited or nonexistent. The challenge is to promote these programs, linking them to other service delivery systems or by integrating them into existing community-based programs. That is where our organization comes in ... provide these caregivers with a concise and consolidated resource while offering the support and guidance that they and their disabled children need on a daily basis.

Support groups in combination with respite and other services, have positive direct effects on health behavior practices and assist caregivers in remaining in their caregiving role longer, with less stress and greater satisfaction. Support services for caregivers - including counseling, information and ongoing support - have been shown to deter institutionalization of their ill and/or disabled family member.

STATISTICS

Estimates indicate that 25% of the entire American workforce provided caregiving to a loved one during 1996, and a study by the U.S. Department of Health and Human Services in 1998 estimated that 1 in 3 Americans (or about 52 million people) care each year for 1 or more chronically ill or disabled family members of all ages. When it comes to caring for children with special health care needs under the age of 21 whose serious or chronic physical or developmental conditions require extensive preventive and maintenance care beyond that required by typically healthy children, the caregiving responsibility usually falls to Mom.

Studies show that among female caregivers, approximately 49% suffer from exhaustion, anxiety, clinical depression and other symptoms associated with emotional stress. About ½ of these primary caregivers provide their child's care with no outside assistance what-so-ever, and only an estimated 10%-20% use formal services through public or private agencies. More than 50% of these caregivers juggle work, family and caregiving responsibilities, resulting in work disruptions and lost productivity. This caregiver role results in enormous emotional, physical and financial hardships, even though it is willingly undertaken. Worries over paying for the long-term care of a chronically ill and/or physically disabled child especially plague middle to high income families who are not eligible for public benefits, yet cannot afford the out-of-pocket costs of care involved. Caregiving poses an even greater financial challenge for women workers, due mostly to lost wages from reduced work hours, time out of the workforce, family leave or early retirement.



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MOM AS CAREGIVER

Moms don't abandon their caregiving responsibilities because of employment ... instead they "cope" to the best of their abilities with the combined pressures of caring for a sick child, their need for income, reliance on inadequate public programs and fewer employment-related benefits. Moms in general believe it is a privilege, not just an obligation, to do so. Stress in family caregivers is inversely correlated to income: the less income a caregiver has, the more stress she is likely to experience. This often times creates a significant economic impact on the entire family.

Caregiving is a multi-faceted role, can be an emotional roller coaster requiring a wide range of support, and yet remains the backbone of our long-term care system. Caregivers commonly experience a sense of burden, fair-to-poor physical health and high rates of depression. Caregivers use prescription drugs for depression, anxiety and insomnia 2 to 3 times as often as the rest of the population. Family caregivers are less likely to practice preventative healthcare and self-care behavior, sacrificing their own needs to meet the needs of their chronically ill loved one. They are at high risk for sleep deprivation, poor eating habits, failure to exercise, failure to stay in bed when ill, postponement of or failure to make medical appointments, and excessive use of alcohol, tobacco and other drugs for depression. Exhaustion, worry, inadequate resources and continuous care demands are enormously stressful.

"THE M.O.R.G.A.N. CENTER"

The M.O.R.G.A.N. Project proposes to provide these needed services and programs, right here in our own South Brevard area. We envision our first "M.O.R.G.A.N. Center" as a prototype for expanding into other communities, in other states, eventually nationwide! Which means that many thousands of caregiver-Mom's who are members of that ever-increasing "secret club" - women caring for their chronically ill children with physical disabilities - can be so positively impacted with this future vision that is so dear our hearts!

Caregiver support services include information, assistance, counseling, respite, home modifications, assistive devices, support groups and family counseling. Support services can make a real difference in the day-to-day lives of caregivers and their children with special health care needs. The isolation felt while caring for an impaired child at home can be devastating in itself. Studies have shown that this is eased by attending support group meetings with other families in similar situations. Support groups provide emotional support and caregiving tips, as well as information on community resources from others who have learned from experience. Support groups bring together friends and family members who meet regularly to share insights and discuss practical solutions to common problems. They are an excellent source of information on available resources. Support groups also provide caregivers with the opportunity to give and receive encouragement, understanding and support from others who have similar concerns. Interacting with other caregivers of children with special health care needs can be a great help in reducing stress, and in turn the associated physical and emotional problems that follow. Support groups and retreats can be educational, inspirational, motivational, entertaining and informative.

Through the objectives of The M.O.R.G.A.N. Project and with the assistance of like-minded individuals and organizations, many thousands of women in the disability community will be able to find partners, mentors, advocates, teachers, friends ... other members of that "secret club" to share their experiences with, their trials and tribulations, their hopes and dreams, their joys and accomplishments, their sorrow and grief. Family caregivers are treasures who are not always recognized for the incredible work that they do. The M.O.R.G.A.N. Project will be able to assist in so many different but necessary ways to help them to care for these very special, special-needs children. Together, we can take this "secret club" and turn it into a "spectacular club" instead ... empowering these women with the tools that they need to make their lives and their children's lives more productive and rewarding.



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SPECIAL NEED "101" PAMPHLET

The M.O.R.G.A.N. Project has identified caregiver support as a high priority. A project tentatively entitled "Special Health Care Needs in Children ~ A Comprehensive Guide for Parents" is planned. This project will produce **5,000** printed & bound comprehensive reference manuals for parents to be given when their medically-fragile child is diagnosed with life-threatening and/or disabling disorders, as well as a corresponding **interactive website** and internet resource service.

Children diagnosed with chronic illnesses and associated disabilities require a multitude of complex services to meet their critical medical needs and to ensure their quality of life. Parents of these special-needs children face unique emotional and practical challenges every day ~most of which are seldom fully addressed by the medical community~ and parents' most compelling questions remain unanswered. According to the *National Organization for Rare Disorders*, over 5,000 different rare diseases alone collectively affect 20 million Americans. However, in some cases specific disorders only occur in less than 1 in 30,000 live births, leaving parents feeling isolated and confused.

Currently there is no comprehensive resource manual for parents to educate themselves about the myriad medical and support services available for their children with one of a multitude of disabling disorders, such as (1) early diagnosis & intervention; (2) preventative care; (3) contraindications of different treatments; (4) specific questions to ask medical professionals; (5) educational programs, policies & procedures; (6) resources for children & families;(7) medical terminology & acronyms;(8) support groups; (9) clinical trials; (10) family/medical conferences, etc.

Our proposed guide and companion website will address these issues in a concise and straightforward manner, with the goal of providing parents with a better understanding of the different approaches in healthcare available, as well as strategies and coping mechanisms for living successfully with these disorders. In providing these families with advance knowledge of the many issues that their children will be facing and offering suggestions on what questions to ask providers, parents will be able to take a proactive approach to their child's care.

In the research stage, information will be compiled from surveys of parents, support groups, medical professionals, etc., as well as from the review of published medical papers, journals and internet resources. An emphasis will be placed on conducting these surveys by electronic communication means wherever practicable, such as email and internet newsletters, to reduce the associated costs.

This information will be assembled by subject and transcribed into individual chapters, addressing the various issues in an easy to follow format. In the product production stage, this will be written into an approximately 80 page resource manual comprised of 10-15 individual chapters addressing the issues outlined above. The comprehensive guide will be professionally printed and spiral bound with a soft cover.

In the dissemination stage, the companion website will be set up in a comparable format, along with relevant links to other resources. A supply of these pamphlets will be provided to OBGYN's, Pediatricians and other pediatric physicians involved in the diagnosis and treatment of pediatric diseases and disorders. Additionally, we would like to have every Children's Hospital supplied with these, as well.



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