As Hali grew up, we were blessed with a great school situation, supportive family members and friends, a community of faith, and a committed team of doctors. As we have traveled the country with this mission, we have been made aware that few families like ours have all of those things to draw from and lean on, and some families don’t have any of them. That’s how our wonderful gift from God helped forge The HALI Project.

We first recognized that while Hali was receiving excellent services through the Canyon Independent School District, there were very few resources available to help parents navigate the many systems we find ourselves involved with when our kids have special needs. As we met other parents, we found their stories to be very similar to ours.
Those experiences led to the first part of our project—Empowered Parents. This program taught parents how to first come to grips with the reality of their situation, then dream new, appropriate dreams for their kids. From there it addressed understanding the ongoing emotional journey and how it affects daily life, balancing care for all family members, and conflict resolution among other things.

We have been blessed with many opportunities to teach this material in many places, but it wasn’t long until we realized that we needed to get to families earlier, preferably before their children started school. The reason is because by that time many have already formed ways of managing life (some not all that healthy) that are difficult to change once they are entrenched. So we began to look for ways to get to families earlier in the process. Not long after that, we met Dr. Shari Medford—a pediatrician who is also the mother of Erin, a young lady with Down Syndrome.

After attending our workshop, Dr. Medford asked if it would be OK to give our number to her families who have children with special needs. Over time, our partnership evolved into her scheduling “well child” appointments for her patients with special needs on Friday’s and me spending that day in her office, meeting and offering help to those families.

After several years of talking about this model in various settings, we were invited by The Boys Town Institute for Child Health Improvement to partner with them to build the capacity of the medical homes participating in their learning collaborative. Through this pilot program, 6 pediatric practices in Nebraska were chosen to house a Professional Parent Coordinator to serve as the “hub” for coordination of family supports in the community, as well as assure that all services are fully integrated into the primary preventive health care model.

Parent Consultants with similar experiences are simply better able to understand the realities and frustrations parents with special needs present and can offer both empathy and practical advice. They help families access and coordinate specialty services, link to community resources, overcome barriers, and navigate the various service systems. Simply by their presence, Parent Consultants can help to improve the family-centered and cultural competence qualities of a medical practice.

After practices identify which parents they think would do this job well, we want to make sure the parent is connected to their local and state family support organizations. This connection opens the door for them to knowledge of local and state resources and how to efficiently access them. When those things are done, the parents and any office staff that is interested participates in a two-day training. The training focuses on personal emotional aware-

My friend and teammate Hali

If you were to walk up to someone in the small town of Canyon, TX and ask if they have seen “Hali” lately, they would probably reply with “Hali who?” BUT! If you walked up to someone in that same small town and asked if they have seen “H-Baby” lately, they would know exactly who you were talking about. Hali, or H-Baby as I call her, is my friend and she has touched many different lives in so many different ways. I have known H-Baby for years, but the majority of my experience with my amazing friend is through the Canyon High School volleyball program. H-Baby was our volleyball manager by title, but to the team she was so much more. She was our cheerleader, our pep talker, our #1 fan, our comic relief on the bench when things weren’t going so well, but most importantly, she was everyone’s best friend. Every day in the hall at school, at practice, or wherever you happened to see H-Baby, she always greeted you the same way. She always has the best, most genuine infectious smile on her face and literally runs to give you a big hug and high five. One of my favorite things about H-Baby are her nicknames. She gives nicknames to her friends that only she calls us. For instance, I am T-Baby. We also have a Tree, KK, Scooter, W-Baby, T-Baby Jr., S-Baby, Daddy D, and the list goes on. These nicknames are special and treasured by all of us. You know you have made it in H-Baby’s book when you get a nickname. H-baby loves people unconditionally. If you have made mistakes in your past or have had problems, she will love you just the same. She has touched my life in many ways, but mostly what Hali has taught me is that I need to strive to be more like her. She is so happy and loves life. She also treats people with respect and loves them unconditionally. Hali tries to be good, but if she messes up she gets upset and wants to fix it immediately. Also, She never wants to disappoint anyone. I have been sick recently and I ran into H-Baby at one of our teammates wedding showers. Ever since then, she has been calling and checking up on me on facebook to make sure I’m feeling ok. She genuinely cares and loves me, and that has touched me so much. H-Baby inspires me to be a better person, and I hope I love and treat people at least half as good as she does. I wish everyone had a friend like Hali.

-TIA SCHMIDT "T-BABY", HALI’S FRIEND AND TEAMMATE.
ness as well as learning to discern where another parent might be on the emotional journey when their children have special needs. We also have training segments focusing on conflict resolution and managing difficult conversations. Following the initial training, we use monthly conference calls that include the Project's leadership group and the parent consultants. During this time, we deal with any practical challenges the parent consultants are experiencing. They also share (while protecting a family's right to privacy) challenges and successes they have experienced which gives the team an opportunity to learn from each other. We use the last part of the call to provide ongoing education by addressing common challenges the parent consultants are experiencing or teaching a new skill they can use in working with their families.

Parent consultants can also call or correspond through email to get help at any time. One of my greatest concerns is the emotional well-being of our parent consultants. These calls and emails address any “cases” the consultant wants advice on, the practical nature of how the consultant is blending into the routine of the practice, and most importantly, how this work (which can be very emotional at times) is impacting our consultants and their families. Because of the support the parent consultants receive, they are not another person to be taken care of in the practice. In fact, the parent consultants sometimes become emotional support for members of the practice in challenging situations because of their credibility as parents and training in emotional support.

On a small scale to this point, we have seen this program address many of the concerns reported by pediatricians when it comes to serving children with special healthcare needs. Having a parent consultant available frees them of the responsibility of searching for resources outside of the medical community. It also allows the pediatrician to connect their parents to another parent who has both the time and the practical experience of being on this journey as well to support them along the way. This support may begin during an office visit but in many cases will lead to support relationships that spread beyond the medical arena to school, resources, and community support opportunities.

As word spreads about their work in their communities, our parent consultants start to be seen as “community resources” by others who work with our families. Several of our consultants have received referrals from other pediatricians in their community as well as other agencies. I believe this is important for two reasons. First, most family support groups lack any opportunity for direct contact. They depend on a referral which is rarely followed up on for multiple reasons, not the least of which is a “To Do” list that is already too long. Second, in a time of increasingly tight budgets, the opportunity to partner with multiple local groups can produce greater results with fewer dollars.

There are multiple benefits to the practice. First, the pediatrician is allowed to focus on his/her area of expertise—medicine—while providing the family with a high quality resource to meet their other needs of relationship, support, and resources. The presence of the parent consultant frees the doctor to see more patients by reducing the amount of time spent with each patient while adding to the quality of the visit for the family. This impact can improve the doctor’s “bottom line” by spending more time providing services that are reimbursable. We believe it can also improve the doctor’s quality of life by allowing them the opportunity to go home earlier if they so choose.

In our Nebraska practices, our consultants are also focusing on the “no shows” in the practice. We believe that contact from a parent encouraging the follow-through on an appointment will have a greater impact on a parent (especially another mom) than a computerized message or even a live call from office personnel. By increasing the efficiency of staff time and lowering the “no show” rate, we believe that our consultants will begin to pay for themselves within the first year of their work. Another area where we have found our parent consultants can be of help is in encouraging childhood immunizations in some populations and neighborhoods. Whether it’s due to language barriers or misinformation, some practices find that their immunization percentages are low. A conversation with another parent can help to lower the anxiety levels that some parents feel in situations like this.

The foundation of our work and our training of others is a two-day training that begins with the emotional process, then leads into communication, problem solving, and conflict resolution skills. We believe that if we can help people understand the emotional process and where we are in that process at any given time, we can be in control of those emotions. As we train partners to work in practices across the country, we stress the importance of knowing where they are in the process and of being able to discern where the parents they are working with might be as well. Most would agree that managing our emotions is the key to communication. And positive, healthy communication will be the key in building relationships with the many people and groups our families will interact with throughout their child’s life.

Our belief is simple, though it may be controversial to some. We believe God made Hali exactly the way He wanted her, which means He has a great purpose for her and He has entrusted her care to us. As her parents, it’s our job to help her reach her potential so that she is able to live out His purpose—and that will be the best possible life she can have. And we want to share that hope and belief with as many families as possible.

The article is dedicated to the memory of Marvin Thomson, Hali’s grandfather and her biggest fan. Marvin passed away just as this issue was going on line and we wanted to make sure this message of remembrance was included.