

The Benefits of Local Support

3-Part Series: Part 1

By Margie Boyd, Founder and Executive Director, Tyler Type One Diabetes Foundation

I sat at my kitchen table completely overwhelmed surrounded by life-saving supplies piled high. I had been saving up my tears for this moment. I was finally alone. **There was no one around that needed me to be strong** so I buried my head in my hands and cried like a baby.

I managed to hold it together earlier in the doctor's office as **I watched big tears roll down my sweet 8-year-old son's face**, not because he gave himself his first insulin shot, but because he was now disqualified from joining the military and following in the footsteps of his Marine grandpa and Paratrooper dad. At that moment, I knew this was not the diabetes I was used to hearing about on TV and in the media. **Type 1 Diabetes was more sinister—one that kills and steals a child's dreams.**

So that evening sitting alone at my kitchen table, the day unfolded again over and over in my mind. The medical staff, friends and my family had all been tremendously helpful, but I was still unsettled. **All I wanted to do was meet and talk with someone who was actually living it, someone who knew first hand these overwhelming feelings. I needed hope.** I wanted to connect with another mom or dad that had walked in my shoes and lived to dance another day. I needed to see a child or person living a full life with Type 1 Diabetes, playing sports, swimming and surrounded by friends. I needed an empathetic hug and to hear the words, **"You are not alone. I know exactly what you are feeling right now. I am here for you."**

Over the next week or so I discovered the support of complete strangers through the DOC (Diabetes Online Community). Knowing I could go online anytime and find someone awake at 2:00 AM that could give me some experienced advice was invaluable. **That is a level of support that everyone can and should have access too with a click of a button. And there are some excellent site's out there. A few that I've found most helpful are T1D Mod Squad, Diabetes Daily, Children with Diabetes and Beyond Type 1 just to name a few.**

On another level, the word got around my community and several Type 1 moms and dads found me and reached out. **That provided a tangible comfort and support that was on a whole new level.** I not only talked with them but I met with them face to face. We become instant family. **We not only shared this disease, we shared our lives.** We shared supplies when we were running short, we shared our pain as well as many funny stories that only we could understand.

It turned out to be a win win for the medical community too because we called each other for advice about the little day to day things that Endos and diabetes educators don't need to be answering. "How many carbs are in a Walmart cupcake? Do you let your child spend the night at their friend's house? What about managing Type 1 and school? What test strips need the smallest blood sample? What finger poker makes the smallest hole? The list of questions and concerns were endless.

It took about a year after my son's diagnosis to fall into a groove and I started to gain a little confidence. One thought that I just couldn't shake over that first year was the fact that every week someone new in our hometown was experiencing the same overwhelming feelings and

heartbreak I had that first day. **Type 1 was no respecter of persons and each one diagnosed would feel like they had been blindsided. Empathy kept tugging at my heart** because I knew what they were going through or would go through in the future. Sometimes in life **when we face difficult situations, the best therapy can sometimes be to turn around and help someone else.** It not only keeps our mind from focusing too much on our own problems but it helps us find deeper meaning and purpose in our lives knowing we have what someone else needs. **By making ourselves available, we have the ability to be the answer to someone else's prayers.**

My close friend Becca and I started tossing around the idea of **developing a formal system for reaching out to those newly diagnosed in our community.** Even though her family wasn't affected by Type 1, she was a huge support and let me dream out loud. Every visionary needs a friend like her. We sat many mornings on her front porch hashing out the possibilities of starting an organization. We knew many Type 1 families eventually connected through school or mutual friends in a smaller community but **we wanted to reach them when they were the most vulnerable, and the most overwhelmed during the first hours of diagnosis.** That is when the connection has the most impact.

We decided to gather a few more friends and talk with our local Pediatric Endocrinologist, Dr. Luis Casas and his staff. **They were an exceptional medical team and understood the value of peer support.** They offered to tell their patients about our group if we got started. Also, if the patients gave their permission for us to contact them, no privacy laws would be violated and it would enable us to make the first move to reach out to them immediately instead of waiting for them to call a number on a card. This way, **our brochure would come alive when we walked in the room and we could make a face-to-face and heart-to-heart connection.**

Now things began to get real. **Our "good idea" was moving to the next stage of development, so we knew we needed to get organized.** I had heard of several support groups that had started locally in the past but after a while disbanded. These groups had been started by passionate, loving people who wanted to help. The problem with that model is that passionate people get tired and burned out after a while if no one else steps up to help lead. **Passion and empathy are great catalysts for getting something started** but building a longterm, sustainable support system needs a solid mission, partners who share that mission and infrastructure. I turned to a local woman who was known as the nonprofit angel and expert in our town, Dawn Franks. **She had helped many take their "good ideas" and flesh them out making sure they had the substance they needed to accomplish their mission.** Like a true professional, she did not always tell me what I wanted to hear, but she told me the truth. And truth is a solid foundation if we will embrace it and build upon it. **Her advice and wisdom were invaluable and still are today.**

So in late 2009, with an established mission to provide vibrant and consistent local support to the Type 1 community in our hometown of Tyler, TX, we put a board in place made up of Type 1 parents as well as friends who believed in our mission, incorporated with the state of Texas and **Tyler Type One Diabetes Foundation was born.** Little did we know that we would hit the ground running a few weeks later with our first family to support...**a 9-month-old baby girl named Faith, diagnosed with Type 1 Diabetes only hours from death.**

The Key to a Thriving Support Group

3-Part Series: Part 2

By Margie Boyd, Founder and Executive Director, Tyler Type One Diabetes Foundation

Susie and her son Jeremy thought they were going to just another quarterly Endocrinologist appointment...something they had been doing for over 17 years since Jeremy's diagnosis at 16-months-old. When the appointment was over, Dr. Casas turned to them and said something to this effect, **"Well, today is the day. You have been talking about reaching out to those who are newly diagnosed, and today, I have someone that wants to meet you if you are willing and have the time."**

Susie, was the President of the board for our newly formed local non-profit, Tyler Type One Diabetes Foundation. She was also a pastor's wife and **loving people through hard times was second nature to her** and Dr. Casas knew it. He also knew that **Jeremy was a healthy, articulate, kind-hearted young man who would embrace the opportunity to share his story**. As a matter of fact, they were not even originally scheduled to come in that day for an appointment, their normal appointment had to be rescheduled and they just happened to be there that day...the day **9-month-old Faith Wilson, the youngest child to ever be diagnosed with Type 1 Diabetes in Tyler** was recovering in the Children's Miracle wing of the hospital near where Dr. Casas had his office. The timing could not have been more perfect for visiting Faith's family who were still in shock and overcome with fear.

When Susie and Jeremy walked in, Sarah, Faith's mom, said, "It was like hope walked in the room. Jeremy was smiling and healthy. He told me that since Faith was diagnosed so young and she was going to grow up with Type 1, it would be as natural as brushing her teeth one day." Susie and Jeremy passed around plenty of hugs and hope that day in Faith's hospital room...**face-to-face, hand-to-hand, shoulder-to-shoulder...tangible hope.**

This is an example of what I call the "cycle of support". Sharing our experience and knowledge that have come out of difficult circumstances with those that desperately need it not only helps them but it also helps us find deeper meaning and purpose. Everyone in that hospital room that day experienced a level of support and comfort that can only be found in the cycle of support.

We watched it unfold in our local community in the coming weeks and months. Working hand in hand with Dr. Casas and his staff, **we developed a formal system of visiting newly diagnosed families within 24 hours of diagnosis**. Almost all gave their permission for us to visit them the same day their child was diagnosed. **We discovered our window of opportunity was about an hour or so while they were waiting to see the Diabetes Educator** after their initial meeting with the doctor. I would get a call that permission was granted and the ball would begin to roll.

We created a "gift basket" filled with good foods and snacks for treating lows that other Type 1 families had recommended. **We wanted our support to be very practical and immediately helpful**. We always had 4 or 5 baskets on hand ready to grab and go to the hospital. Susie, one of a board members, had a designated space in her guest room at home that she kept stocked with supplies so she could put a basket together at a moment's notice. Several of our board

members, Susie, Mia, Christel or myself would make the delivery and visit depending on who was available during our window of time.

Delivering the baskets was bittersweet. **It never grew old walking in that door with a basket. Parents would have tears streaming down their sweet faces yet the child's face would light up knowing that the gift basket was just for them.** Hugs came natural and so did the words, "Don't worry. You aren't alone. We understand exactly what you are feeling. We are here for you."

We took the opportunity to write down their name and email and invited them to our monthly support group. **After making a face-to-face connection, almost everyone we visited found their way to our monthly gatherings.** We weren't just a printed card given to them at the doctor's office. We now had a face and a name. **This turned out to be our secret sauce for building a thriving support group.**

Meeting people face-to-face in one of their darkest hours **was a privilege and we never took it for granted.** Even though, the meeting would only last about 5-10 minutes, we were careful to simply love them and surround them with the support they needed in that moment. **The only thing that really mattered to us was connecting with hurting families by providing an empathetic hug and shoulder to lean or cry on and giving them our basket of snacks to help them on a practical level.** We were so grateful to Dr. Casas and his staff for entrusting us with the opportunity to introduce these families to another layer of support. We had a healthy respect for one another. We each focused on doing what we knew best.

I received a call one day from Dr. Casas that a teen named Lizzy was in the hospital in DKA and wanted to know if we were available to visit her. **I was always looking for an opportunity to take Type 1 kids or teens with me** to deliver our baskets. I homeschooled my boys so I could take my son Jake with me often. This time I reached out to a young teenage girl named Carlin, who had asked if she could go with me the next time I delivered a basket. After speaking with her parents, we arranged to meet and go together to visit Lizzy. **Carlin was a bit shy about people knowing she had Type 1 which was not uncommon. We had talked about how going with me might give her a new perspective.** Since this was her first visit, Carlin let me know she may not do much talking. She wanted to watch this first time. I was fine with that. I was just glad she was with me and knew the impact it could have on Lizzy and her mom.

When we walked into the room and saw Lizzy laying there, having been in a fight for her life the night before, **Carlin didn't waste any time talking to Lizzy.** I was so surprised. I just let it unfold naturally. I let Carlin talk all she wanted. **I recall Lizzy's mom asking Carlin more questions than she did me!** It was so authentic and natural for Carlin to share her story with Lizzy. She even pulled aside her shirt and let Lizzy see her infusion site where her pump was attached to her body. She demonstrated her pump, talked about running track in school and how that affects her blood sugars and many other details that only those living with Type 1 would be interested in. It was beautiful. I loved it. **When we left the room, Carlin turned to me and said, "Wow! I want to do that again. That was awesome. Can I go with you again sometime?"** That my friends is priceless!! **That is the cycle of support** that having a local support system in place facilitates. **It simply helps create the opportunity to connect those in need with those who have WHAT they need.** Everyone wins.

Start a Local Support Group in Your Community

3 Part Series: Part 3

By Margie Boyd, Founder and Executive Director, Tyler Type One Diabetes Foundation

Tyler Type One Diabetes Foundation went from a “good idea” to a thriving support system in a few months time largely **due to a partnership with our local medical community and putting an infrastructure in place** that was built to last. Today, we have been consistently providing support every month to our Type 1 community in Tyler, Texas over the last 7 years. We saw a need and put a plan into action to meet that need. **You can do that too in your community!** We hope that you can glean from what we have learned over the years.

First we established that **we wouldn't simply be reinventing the wheel and duplicating existing services in our area**. There were some national organizations that offered Type 1 support programs as a supplement to their main mission but **none had local support as their primary focus**. So we took the next step and decided it was worth our time and effort to pioneer a new local organization to try and meet that need.

Interestingly enough, **we were approached by a well known national organization to become their local chapter after we had laid the foundation for Tyler Type One**. They assured us that we could still give our gift baskets out to those newly diagnosed in addition to our new event and fundraising responsibilities if we made the change. A nice salary also came along with their offer for our Executive Director. But the problem was **we didn't want to change our focus from local support to the cure**. Sure we wanted the cure as much as anyone but **we also felt strongly that providing local support could help those living with Type 1 arrive at the cure one day stronger and healthier**. So we said, “Thank you but no thank you as nice as we could and **stuck to our mission**.”

If you are considering starting a support group in your hometown, **sticking to your mission is one of the hardest things to do**. Sure, it's fine to add a few items to your plate, but just like serving a balanced meal, you must make sure to always compliment or support the main course...your mission. **Unless you make it a priority to stick to your mission, there will be a thousand rabbits to chase and a million little foxes to steal your time and energy**. You have to constantly evaluate new ideas and make sure they correspond to your original mission or before long you could be spending 90% of your time on events and programs that have nothing to do with your original mission.

Once you have determined that **no one else has your exact mission locally**, then consider taking the next step and **gathering some friends who might want to partner with you to put your “good idea” into action**. That is exactly what we did. Several of us even got together to pray about it just to get to some extra guidance before we jumped in. I tell you this because something interesting came out of that time together that helped us fine tune our mission. Even though our founding board members were all Christians, one of the first decisions we made was that Tyler Type One would NOT be an official faith-based organization. **We wanted to make sure that anyone who needed help managing their child or themselves regardless of their faith**, would feel comfortable coming and would have the support they needed. **Our mission was not about saving souls**, it was about saving lives. We would have the privilege of loving people in the process.

To imply that we knew what we were doing would be an understatement, we did NOT. **We just kept taking baby steps.** My personality likes to take giant steps. So that is why **a board of directors is so valuable.** They provide oversight, stability and accountability. It has been said, **“The health and strength of a nonprofit is dependent on the health and strength of its board.”** There is a lot of truth in that statement. I decided early on, as the original initiator, that I wanted this to be a team effort. I did not want this to be “my baby”. I wanted this to be “our baby”. **I wanted to share ideas, effort and responsibility.** I wanted to surround myself with like-minded individuals and work together to accomplish something that hadn’t been done before in our community.

Of course, at first, I was more than willing to take the lead but I told the board from the beginning that I wanted to be part of a team. **When I officially became the Executive Director, I laid down control. I laid down the right to vote.** From that moment forward, the board could vote to fire me as the ED and replace me if they wanted or needed to. I knew that from the moment I accepted the position of ED. On the flip side **I knew Tyler Type One Diabetes Foundation would have a greater chance for growth and success this way.** The collective creativity and resources would be far more valuable, not to mention the depth of friendship, meaning and purpose that we would experience with one another.

Together we developed our core programs based on the missing support elements in our community: **1)** Partnering with the local medical community to reach out to the newly diagnosed within 24 hours when possible. **2)** Hosting a monthly support group for children, families and adults with Type 1. **3)** Offering a Type 1 focused Diabetes 101 class for grandparents, teachers, school nurses, babysitters, extended friends and family. Then we built a budget and a fundraising plan to be able to carry out our mission. We just kept taking baby steps. (If you interviewed the board at the time, they would probably tell you that we “just kept taking giant steps” which was more my style at the time. I’ve since learned the value of baby steps.)

As with any nonprofit, fundraising is a necessary aspect. The board’s responsibility is to see that the funds are raised in order to be able to carry out the mission. The Executive Director will then have the staff and funds to successfully be the hands and feet of the organization. **Understanding the differences in the role of the board and the ED are vital to be a healthy nonprofit.**

Sources of income that make it possible to develop and offer support programs to your Type 1 community can be found through **individuals** who want to support your cause, **corporations** and local **businesses, diabetes companies,** event **sponsorships, membership dues,** government **grants** and local **foundations. Sharing your mission and vision with others and being able to articulate your financial needs is essential for any person working with your nonprofit.** We have received generous gifts from those in our community but someone has to be willing to make the ask or fill out the grant application. These are all skills you must learn to do if you want to be able to offer your programs.

Even if you decide that officially starting a nonprofit is not the route you want to take in offering support in your community, you can start a club or an association using similar principles. This will help you have a greater opportunity for long term success. With a lot of hard work using this model, I’m happy to say, since 2009 we have been fulfilling our mission

locally. **We have the longest running, monthly support group for people with Type 1 Diabetes in our area.**

Over the years, we have received over 100 requests to use this model to help start support groups around the country. **A few independent affiliates have spun off from our group in California, Louisiana, Texas, and Kansas City with some amazing individuals at the helm.** Some of those groups continue today meeting their own community's needs for support. But we discovered very quickly that **most who contacted us simply wanted to start and host a consistent gathering for the Type 1's who live in their area.** They were not necessarily interested in starting a full fledged nonprofit organization like we did. **You have to decide what is best for your community** based on the need, your available time, resources and people who are willing to partner with you.

For us, our goal has always been to develop a system of support for the Type 1 community that had **infrastructure for longterm sustainability.** We knew until a cure was found, there would be a need for our services. We wanted to build something that would be around long after our own Type 1 children were grown. To quote Michelle, one of our adult Type 1 members who has lived with it for over 35 years, **"We do grow up...but not OUT of it. There will always be a need for support."**

Unfortunately, a few years ago, our beloved local endocrinologist moved to another state and the hospital here hasn't been able to replace him yet. It has put a serious dent in our support group attendance since we no longer have that natural influx of newly diagnosed families coming into the group. It used to be normal to have 50-75 attend each month and now we have half that on the average.

It wasn't until after Dr. Casas left that we fully realized the blessing we had experienced over the past few years through his support and partnership. Having an endocrinologist that goes out of his way to make sure his patients have the peer and social support they need was unique to say the least. He believed and supported our mission from the beginning. **Having newly diagnosed families flowing from the doctor's office straight into a local support group was like a natural current in a stream.** It kept us moving and from becoming stagnant. Also, there were always older more experienced people with Type 1 at the meetings to take the younger and newer members under their wing and help them along. **It facilitated a never ending cycle of support.** So if you are thinking of starting a support group in your community and you want it to thrive, **never underestimate the power of partnering with the local medical community.**

From the beginning we **also wanted our model to be duplicated or adapted** in various communities. We are happy to share what we have learned over the last 7 years and offer a PDF with our tips and keys for building a successful local support system. Regardless of whether you simply want to meet once a month consistently with your Type 1 community or launch a local nonprofit, **download our PDF.** We hope that you can glean the help you need to support your local Type 1 community.

Many adults in our group that were diagnosed at a young age have told us how alone and unsupported they felt before coming to Tyler Type One. **Now we have children that have been in our group for over 7 years that will never know what it is like NOT to have support.** Help make local support for those living with Type 1 Diabetes **the new norm instead of the**

exception in your community. We all need someone who lives it to look us in the eye and say, **“You are not alone, we are here for you.”**

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Margie Boyd Brief Bio: I am the Founder and Executive Director of Tyler Type One Diabetes Foundation in Tyler, TX. Although I graduated in the mid 1980's from Baylor University with a Communications Degree, I fell in love with graphic design after college when I purchased my first Macintosh computer. I've used it as freelancer for over 25 years to support myself and family working with various nonprofits. I am married to Tony, a former fireman, paratrooper and pastor. We have two boys, Luke, a college student who hopes to be a pastor one day and Jake, a high school student who plays many sports and never lets his Type 1 slow him down.