

Silhouettes

Square & Compass Children's Clinic

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"Serving Tucson & Southern Arizona since 1947"



Luke's Story!

Just minutes after engaging in a conversation with Luke, I came to the conclusion that I was talking to a very intelligent young boy. He is an absolute joy to talk to. He carries on a mature conversation with whomever he is speaking with. Luke has lived all his life in Sierra Vista, AZ with his parents and his 16-year old sister. He enjoys playing basketball, playing with nerf guns, and wrestling with his sister. When asked what was one thing he wanted to accomplish in life, he said that it was to learn how to ride a bike.

When Luke was four years old, he failed a hearing test and was referred to Children's Clinics for genetic testing. After extensive testing and research by both the clinic physicians and his parents, they found that he had an extremely rare condition called Van Maldergem Syndrome Type 2. It is so rare that at the time he was diagnosed, he was only the 11th person in the world to have been diagnosed with it.

At Children's Clinics, Luke is treated in the Neurology, Audiology, Genetics, Cardiology, and ENT clinics. He wears a Baha Bone Anchor Hearing Aide which helps with his hearing. An internal hearing aid might be a possibility in the future, but for now he is comfortable with an external one which he can control himself. Due to his condition, Luke has an unpredictable sleep schedule. There are times when he is awake all night, and needs to get his sleep whenever he can get it.

The following was written by Luke's mother in hopes of educating others about her and her family's experience.



Luke's Story from his Mother, Jennifer:

Luke is an 11 year old boy with quite a different story than most children. In fact, there are only approximately 25 kids in the world (as of yet) that know what Luke experiences first hand. Luke was born with what is considered an ULTRA rare syndrome. On January 26, 2017, we finally received the diagnosis. Our little boy was born with Van Maldergem Syndrome Type 2. After years worth of specialists and speculations the one thing we hadn't prepared for was something so rare. As a parent you try to brace yourself for the worst, yet hope for the best. I wasn't sure where this outcome fell into that. Luke's diagnosis came with more questions than answers.

Quickly, we began to immerse ourselves in the facts; the tangibles, if you will. We know that Van Maldergem Syndrome is an autosomal recessive disorder, meaning two copies of an abnormal gene (one from each genetic donor) must be present in order for the disease to develop.

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Van Maldergem Syndrome is characterized by intellectual disability, craniofacial features, auditory malformations resulting in hearing loss, and the list goes on. Today, with a few years of this diagnoses under our belt, we have the knowledge that every case is truly unique. Of course our greatest hope, long term for Luke, is to find a way to receive more research and gain more knowledge about the rare disease that is now a big apart of our story. For now, our comfort comes from our family and the team of Doctors and staff at Children's Clinics.

Luke has been a patient at the Children's Clinics now for 6 years. Our journey began without the forethought of just how important it would be for our son to visit all his specialists in one location. Convenience aside, I have seen Luke go from scared and unsure, to excited and confident when it's time to "go to the doctor". When you have multiple doctors with continuous visits, it brings so much comfort to walk through the same doors and see the same faces. Children's Clinics took the fear and made it fun, for not only Luke, but our whole family.

Today, Luke is feeling more effects from this disease than years before, but his smile still lights up the room and he radiates joy. Luke loves spending time with his big sister Emelia and her friends that so graciously make him feel included. Luke loves superheroes, his favorite being Spiderman.

*Luke is an animal lover, but his dog Olive has his heart, and she loves him just as much. Luke is a typical little boy for the most part, as we move forward we see more evidence of this syndrome than we have in previous years. We are venturing down a path yet to be forged and although the fear could overwhelm us, we choose to see the light in it all. We hope to touch people with Luke's story while educating those who may receive this diagnosis in the future. If you would like to follow Luke's story, you can find us on Facebook under **Raising a Unicorn** or Instagram at **raisingaunicorn_***

*If you would like more information about VanMaldergem Syndrome Type 1 & 2, I invite you to go to our website **vanmaldergemsyndrome.com**.*



Square & Compass Rewards Programs

Square & Compass Children's Clinic is participating in a couple of rewards programs that will benefit the clinic and help our kids at no cost to our donors. With these programs a percentage of your purchase is given as a charitable donation, by the companies involved, with every purchase you make. This is a way for them to give to the nonprofit charities of your choice and at no cost to you.

A great way for you to support Square & Compass Children's Clinic and help our children is to link your Fry's grocery store rewards account to Square & Compass Children's Clinic by visiting **www.FrysCommunityRewards.com**, create an account, sign in, and link your Fry's VIP Card to Square & Compass Children's Clinic, ID #LP381. Fry's Community Rewards requires that participants annually update and select the organization that they'd like to receive the rewards from their purchases. We appreciate you selecting Square & Compass as you renew with Fry's Community Rewards this month.

For those of you who purchase items on Amazon.com, we are also participating in a program offered by Amazon which is called Amazon Smile. By signing on to **www.amazonsmile.com** you can purchase your items at the same purchase price offered by the regular amazon.com, however, by doing so, Amazon will donate a certain percentage of your purchase price to Square & Compass Children's Clinic. When you get to the site it will ask you to pick your favorite charity. Type in "Square & Compass Children's Clinic" in the designated square and click on "select" then whenever you sign on to Amazon Smile, a percentage of your purchases will be donated to Square & Compass Children's Clinic. It's that simple!

Please check back and we will notify you of any new rewards programs that Square & Compass Children's Clinic is participating in. Thank you very much for your continued support!



What's New at the Clinic?

Last year, Children's Clinics, our partner that provides care to the patients here at the clinic, was awarded a \$700,000 Angel Charity Grant. The grant was for renovations that would enable them to expand the Rehab Department and develop a future Autism Center for Excellence.

July 2019 marked the beginning of the renovations. This four-phase remodel included the addition of a private, serene Behavioral Health Suite, sensory-friendly spaces to house a future Autism Center of Excellence, and an upgrade/expansion of the existing Rehabilitative Therapy Department. As of February 2020, nine Behavioral Health rooms have been added along with two Sensory Rooms, three Consult Rooms, one Feeding Room, six Rehab Therapy Gyms, an Outdoor Therapy Space, a Private Family Room, an Interactive Floor in the Lobby, two Toy Wash Rooms, three expansive storage areas, and enough documentation space for 30 therapists.



**Children's
Clinics**

Comprehensive Care for Kids & Teens

This project is on target to be completed in April 2020 and will allow the clinic to provide improved care to the 6,000 children who are treated at the clinic. This coming Fall, Square & Compass will be joining Children's Clinics, in celebration of the Grand Opening of the Angel Charity Center for C.A.R.E and their 30th Anniversary. We are proud to have Children's Clinics as our partner in providing care to children with complex medical conditions and look forward to working together for many years to come.



THANK YOU!

As supporters of Square & Compass Children's Clinic **you** play a significant role in improving the health and lives of **thousands** of children.

In 2019, there were over **38,000** patient visits in the following clinics:

| | |
|---------------------------------|---------------------------|
| Audiology | Occupational Therapy |
| Baclophen Pump | Ophthalmology |
| Behavioral Health | Optometry |
| Cardiology | Oral-Maxillary |
| Cerebral Palsy | Orthodontia |
| Dental | Orthopedics |
| Dermatology | Osteogenesis Imperfecta |
| Developmental Pediatrics | Pediatric Palliative Care |
| Down Syndrome | Pediatric Surgery |
| Endocrinology | Pediatrics |
| Ear, Nose, & Throat | Physical Therapy |
| Feeding | Plastic Surgery |
| Gastroenterology | Primary Care |
| Genetics | Rheumatology |
| Metabolic | Sickle Cell |
| Myelomeningocele (Child & Teen) | Sleep Disorders |
| Nephrology | Spasticity |
| Neuro-surgery | Speech Therapy |
| Neuro-epilepsy | Spinal Cord |
| Neurocutaneous | Upper Extremity |
| Neurology | Urology |
| Neuromuscular | Wheelchair |
| Nutrition | |

In addition, we support Children's Clinics' ancillary services for patients and their families:

| | |
|-------------------------|---------------------------|
| Child Life Specialist | Patient & Family Services |
| Educational Support | |
| On-site Radiology & Lab | Pet Therapy |
| | RN Coordinators |

A Message from the Executive Director

Dear Friends,

We are sincerely grateful to - YOU - our loyal donors for making it possible for us to serve children like Luke. It's only with your help that Square & Compass is able to continue to provide medical equipment, services, and supplies to patients and families who find it hard to meet some of the expenses related to treating children with complex medical conditions.

You can help lessen the financial burden on families that face complicated medical issues everyday by making a tax-deductible donation to the Square & Compass Children's Clinic today. It makes our mission possible and allows us to continue to assist children in our community. Another way to help is by making a bequest to Square & Compass Children's Clinic in your will so that together we can continue to provide aid to children for many more years to come.

This year marks our 73rd Anniversary of serving children with complex medical conditions in Southern Arizona. And in keeping with the vision first realized in 1947, and your generous contributions, we continue to help patients in need on a daily basis. Along with our patients and families, we greatly appreciate your support.

With Gratitude,

Amy Burke
Executive Director

Square & Compass Children's Clinic, Inc.



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