



**"WHY FIT IN
WHEN YOU
WERE BORN TO
STAND OUT?"**

-DR. SEUSS

**Sharing Down Syndrome Arizona
2021 Annual Report**

Our Impact on the People & Community We Serve



From My Heart To Yours

Love, David's Mom

Over my 31+ years of serving families who love someone with Down syndrome, this year has been one of my hardest for sure.

Between the pandemic and how that impacted our ability to meet in person and the way I have seen the devastating effect it has had on parents who have a child with Down syndrome, the quote that comes to mind is this: "That which does not kill you makes you strong."

I am more grateful than my words can tell for the strength I have received from those I have supported. I want to thank all the families who stepped in and stepped up during some difficult times this year. Our new Board of Directors were my rock when I needed them; our Board of Advisors continue to contribute time and efforts into making our organization the best it can be. Our donors, volunteers and staff have given to me so much more than I could have imagined.

The theme for this year's Annual Report and upcoming Sharing Walk is a quote from Dr. Seuss: "Why Fit in When You Were Born to Stand Out?" This quote has great meaning for me about our kids who have Down syndrome and the way they bring goodness to our world, but it also speaks to me with those who have stepped up to help us keep this good work going.

So many of you stand out to me for all that you are willing to do for your kids, family members and loved ones with Down syndrome. Many of you stand out in the way you give so freely your time and talents. And still others stand out to me in your advocacy - wanting to make our community a welcoming place for people with disabilities. The love you have for people with Down syndrome is inspiring and continues to lift my heart. Am I a little biased? Yes, it is my son David who keeps me well-grounded even when times feel hard. I am thankful for him and each of you who inspire me. I am thankful from the bottom of my heart for all of your support in this trying year; the future looks bright for SDSA in 2022, and that is all because of you.

Love,

David's Mom (aka Gina Johnson)



Board of Directors & Advisors

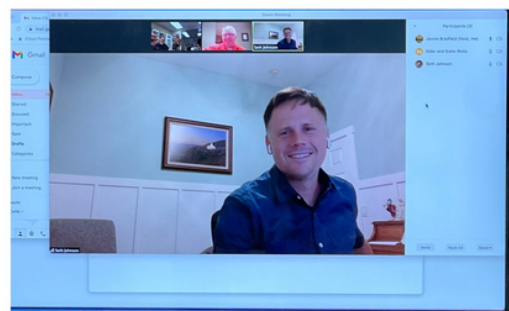
2021-22 Board of Directors: Curt Johnson, President; Leon Ricks, Vice President; Seth Johnson, Secretary; Chris Claridge, Treasurer; Gina Johnson, Executive Director & Founder Sharing Down Syndrome Arizona; Gina Barreras, Medical Contributor; Shannon Ringenbach, Educational Contributor; Naji Haddad, Business Contributor; Kevin Huff, Business Contributor.

Per our bylaws, the BOD meets a approximately (4) times per year. Our annual meeting was held November 29, 2021 at the Mesa office.

2021-22 Board of Advisors: Dave Case, Adam Dixon, Josiah Friedman, Andrea Friedman, Keith Killourie, Sheri Reed, Sylvia Ricks, Barbara Wilkins, Nick Kowalski and Lynn Ferron.

The Board of Advisors meet at least once per year at the Sharing Down Syndrome Headquarters in Mesa, Arizona.

All Board positions are held by people who work with, are related to and are all committed to helping improve the lives of people with Down syndrome.



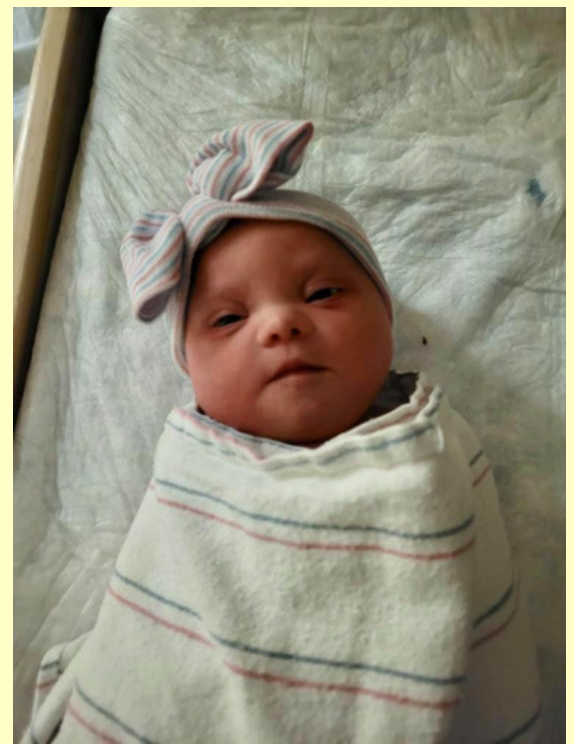
Angels Among Us Program Hospital and Home Visits in 2021



Meet Matias

*We think he has just as many super powers
as Spiderman!*

- Number of hospital/home visits to new parents of a child with DS: 52
- Top 5 cities we reached the most people in 2021 include (1) Phoenix (2) Mesa (3) Gilbert (4) Chandler (5) Scottsdale.
- Provided direct financial assistance for pandemic relief for (8) families, including writing two grants of \$1,000 each from Global Down Syndrome Foundation and distributing those funds to 2 families. Other money contributed came from SDSA from grants.



*I am thankful for one of our newest Sharing baby.
Please welcome Miss Allie. I thought she was beautiful
when I saw her sonogram picture - but
when she arrived - she is even more beautiful than
ever! Welcome Angel Baby! You are perfect.
- Gina Johnson*



Meet Mia

We think she is simply adorable.

Outreach During the Pandemic



While the pandemic is still a factor in 2021, we hosted some smaller, socially-distancing outdoor events. One such outdoor event happened during the weekend of **March 21, 2021**; we asked families to visit the **Gilbert Water Tower** (which was lit up in DS awareness colors yellow and blue) and take photos of themselves.

We shared these photos on social media. We also designed a special t-shirt through Bonfire that read "**See the Ability, Not the Disability.**" People wore these shirts at the Gilbert Water Tower and sent in their photos.

Services Offered During the Pandemic by the Numbers:

- Produced **(3) online parent forums via Zoom** for our families and uploaded the content to our YouTube channel. The topics addressed included (1) Estate Planning, (2) Educational Advocacy and (3) Behavior Management.
- Scheduled more than **(50) Phone Call/FaceTime visits** for new parents to receive in lieu of a hospital visit; or schedule a home visits and use face masks.
- Sent gifts and resources to new parents of a baby or child with Down syndrome. The gifts include books on raising a child with Down syndrome, a Sharing tote bag, a journal and a handmade blanket. Our new parent gifts are valued at **\$125**.
- Produced a **monthly newsletter** (in English and Spanish) to communicate with parents. We email approximately **3,000** people our newsletter each month.
- Scheduled an outdoor **Christmas Party** on Dec. 11, 2021 at Kiwanis Park in Tempe and more than 500 people registered - families enjoyed food trucks, a DJ, Santa, gifts, games, and more!
- Coordinated the '**Bat Cave Experience**' through the Colten Cowell Foundation for **10** families starting Dec. 2021-Dec. 2022. Families and friends get to experience riding in the Bat Mobile and visiting Batman's headquarters.

Online Fundraising Campaigns



Our second annual holiday online auction took place on Black Friday (Nov. 26) through Giving Tuesday (Nov. 30). The auction raised more than \$2,000.

Our families made bids on many one-of-a-kind items, all while supporting our organization at the same time. Giving Tuesday raised additional funds, earning more than \$3600 during this time frame.



Some of the items we auctioned included a signed Devin Booker basketball jersey and a \$100 gift card with 30 minute upgrade to Massage Envy. Another special item we still have available is an estate planning package from Phelps LeClair Law Firm.



For any donations received on Giving Tuesday above \$150, donors were mailed a special license plate frame that reads "I Love Someone with Down Syndrome."



Funding Sources

Grants in 2021 helped SDSA with \$13,250 in revenue for our programs.

SDSA received grants from the *Global Down Syndrome Foundation, Scottsdale 20/30 Club, and the Tempe Diablos*. As of the time this report was written, here are our latest funding sources.

Fry's Community Rewards Program helped raise approximately \$1,000 for 2021

AmazonSmile helped raise approximately \$1,000 for 2021

The Birdies for Charity program by *Thunderbirds Charities* helped us raise over \$900.

Corporate Giving Programs helped raise over \$51,279 for 2021 - including a very generous donation from *Blacker Orthodontics* of \$18,663; in addition, their office donated several toys through a toy drive to give all children a present at our Christmas party.

Individual donations raised \$20,349 for 2021.

SAECO (Smith and Annala Engineering Company) held their 7th annual fundraising golf tournament with SDSA receiving \$10,500 in 2021.

Earnhardt Auto Centers employees donated to Sharing for the final months of 2021 (funding pending).



Pictured from top left to bottom right: Scottsdale 20/30 Club with Gina; Birdies for Charity Thunderbirds Charities logo, SAECO golf tourney participants; Tempe Diablos present SDSA with a check; Blacker Orthodontics delivers toys and a check for our families, Global Down Syndrome Foundation President & CEO Michelle Sie Whitten and her daughter, Sophia. Global DS Foundation gave us a grant of \$2k to help families with Covid relief.

Merchandise

In 2021, SDSA partnered with Bonfire - an on-demand printing company - to produce t-shirts, hoodies, and other merchandise as a way to fundraise and reduce shipping, labor and inventory expenses.

To date, this venture has generated \$595 in sales and \$0 expenses.

We will be using Bonfire going forward on all new products we offer to sell. Our Sharing Walk merchandise will all be sold through Bonfire. Not only does this simplify our efforts, reduce labor and costs, but it gives our families more choices in their merchandise.

Remaining inventory of older items will be sold at on-site events.

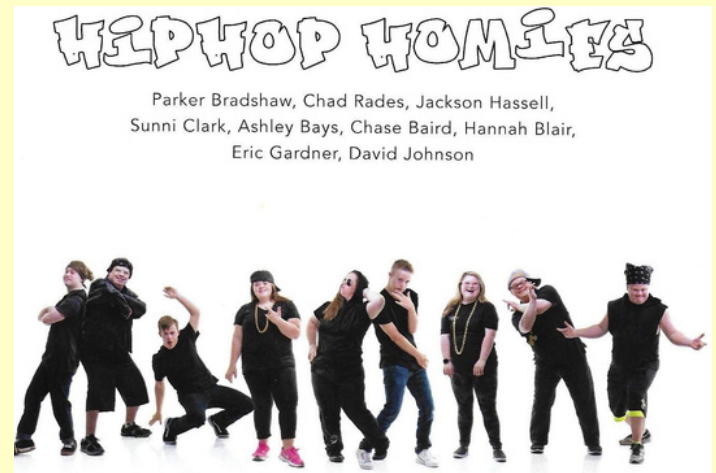


Community Events Promotions

While there were many programs and events SDSA did not host in 2021, our organization did our best to inform our families about opportunities for their loved ones with Down syndrome.

- We promoted a **flag football team** in Sept. 2021 for ages 5-14
- We brought awareness about performances by the **Hip Hop Homies** Dance Group for ages 18 and up
- We shared about **Special Olympics** events, and area **therapeutic recreation** programs in newsletters and social media
- We promoted an **online therapeutic yoga series** for teens and adults with DS
- We shared links and information on webinars about **Dementia and Alzheimer's** awareness from major universities, hospitals, and other centers.

In 2022, we are looking to provide more programs for our families including the re-emergence of Club 3/21, a Walking Club, The Bat Cave Experience (through the Colten Cowell Foundation) and more!



Social Media Campaign DS Awareness Month in October

We appreciate all of the parents who sent in a photo of their children for Down syndrome awareness month this past October. Here are a few of the photos we received.



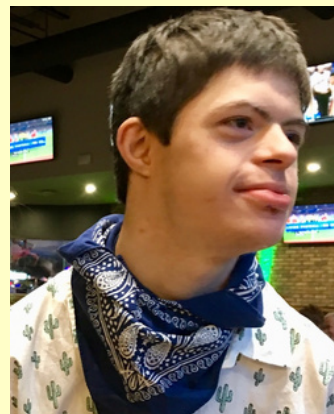
Meet Sean

Sean is a 15 year old from Mesa recently featured on the Times Sq. JumboTron.



Meet Carly

Carly was recently awarded an academic achievement at her high school & loves performing.



Meet Jordan

Jordan is a high school graduate, world traveler.



Meet Josh

He loves cool cars and fun days.



Meet Caden P.

Caden has a cheerful spirit and enjoys boating.



Meet Reece

Reece has a fun personality and loves the beach.



Meet Brian

Brian is an active 15 year old who cheers for ASU!



Meet Emily

Emily is 18 years old and has a contagious smile.



Meet Brisbane

We love her style.

Milestones in Social Media, Marketing and Technology

SDSA increased social media following across its major platforms. Note, all posts were organic, no paid ads or boosted posts.

Facebook - SDSA Facebook followers increased steadily in 2021 and we have 4.2k followers. 82.4% are women.

Twitter - SDSA followers jumped from **186 followers** in October 2020 to **279 followers** in November 2021.

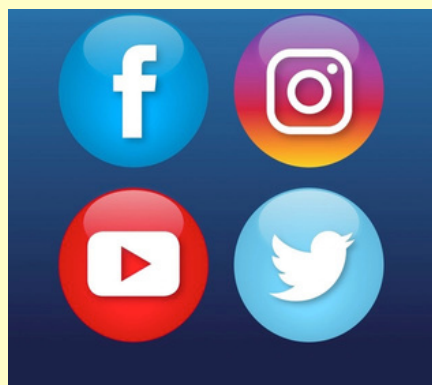
Instagram - SDSA followers grew from **960 followers** in October 2020 to **1,166 followers** in November 2021.

In **Constant Contact**, we have **2,984 email subscribers**, many of whom receive monthly newsletters from the list Proud Parents (English & Spanish). Our open rate for the November 2021 newsletter (*when this Annual Report was written*) was 31% (*8% above the industry average*).

We have **3,962 families** in our customized database as of 11/2021 and **7,253 total people** (all mailing list) in our customized database.

We use two databases to capture our audience; **Salesforce** is used for tracking donors, families, information on contacts; **a customized database** was also created to serve as a mailing list.

In 2020, we relaunched our website and combined two websites into one using **WordPress**.



Impacting Future Leaders



Twice a year, our SDSA ambassadors go to the ASU Sensorimotor Lab in downtown Phoenix and meet with the college students to work in the lab and present to them what life is like having Down syndrome. The students each write their reflections from this experience. Here are some of their insights...

*"It was inspiring to see how Gina talked about how we're all on this earth for a reason and we all have something to offer and can change other people's lives. I liked hearing how each of the ambassadors were involved in various things such as the hip hop homies and what Parker did in school and that he plays an instrument. It was amazing to see how involved they were. I also like seeing how Jordan was after such a major surgery he had. It was great to hear about life from another perspective and hear what people different from myself had to say." - **Danielle K***



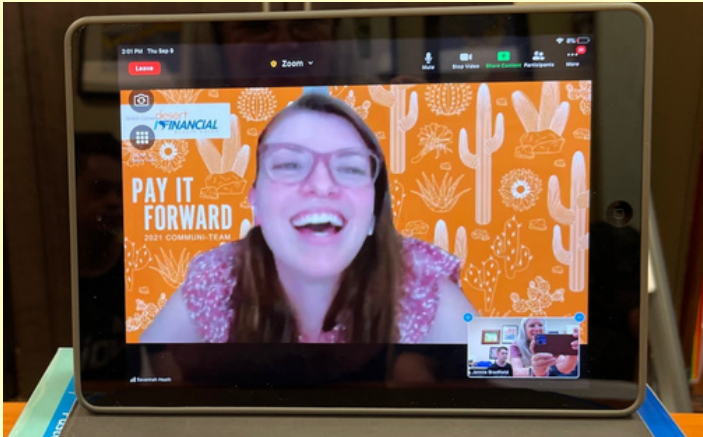
"I am one of the medical students who was fortunate enough to hear from Parker and Eric today about their and their families' experience with Down syndrome. What you all said was so important for us to hear and being able to witness Parker and Eric's infectious joy was just so fun!

Most importantly, the message conveyed by Kay and Barb was incredibly uplifting for me personally. One thing that stuck out for me in particular was how all three mothers mentioned their initial apprehensions at having children with disabilities, but that these apprehensions quickly turned into gratitude for what an immense blessing it is to have a child with Down syndrome. These stories continue to make me realize that we find true happiness only when we live for others, not just for ourselves, and that the sacrifices we make for our children really amount to no sacrifice at all when compared to the joy they bring. I think this is something any parent would agree with, but I truly believe that parents of children with Down syndrome fully exemplify this beautiful ideal. Hearing from you all truly made my day today and I will certainly be thinking about all these lessons in the years to come!"

- Erik V

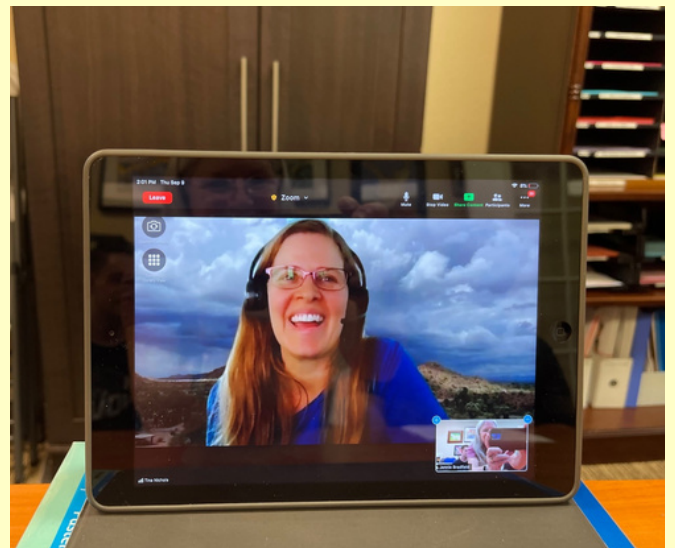
A Visit with Mayo Clinic and Desert Financial Credit Union via Zoom

Other opportunities came this year for us to bring about awareness to professionals at Mayo Clinic and Desert Financial Credit Union employees. We hosted events via zoom for the professionals to interact with our SDSA ambassadors, who shared their experiences about Down syndrome and answered their questions.



"I learned a lot about Down Syndrome and the opportunities available to support and encourage patients with Down Syndrome to thrive. One thing that stood out to me was your discussion about how important it is for a physician to deliver the news to a parent in an uplifting and encouraging way. I hope to communicate effectively with and inspire my patients to live healthy, happy lives. I did some additional research on Sharing Down Syndrome Arizona and am so impressed with the mission and outreach your organization provides. Thank you for all you do to empower individuals with Down Syndrome to live their best lives."

- Alyssa Stockard - Mayo Clinic Alix School of Medicine



From a Proud Parent...

How has Sharing Down Syndrome Arizona made a difference in our lives?

When Samantha was born, we were told within seconds that it looked like she had Down syndrome. We were first time parents and were thrown a curveball with our baby being born with special needs.

The pediatrician at the hospital told us we had to take Sam to so many specialists to see what sort of support she would need and it was emotionally overwhelming. It was hard to just be joyful that we had a brand new baby to love. That is, until Gina Johnson came over!

Gina came to our house when Samantha was just 2 weeks old and hugged and snuggled her and told us how lucky we are and that our baby would grow and accomplish so many things. She gave us hope.

That was just the beginning. We started going to parent support meetings. We met other parents like us. Sharing DS parent meetings always had experts in all sorts of specialties to help support families. Speakers included teachers, lawyers, advocates, doctors, parents with adult children with Ds as well as self advocates! We would also participate in the Easter Egg Hunts, breakfast with Santa, the Sharing Ds fundraising walks and anything our busy schedule allowed us to do. We have also reached out to Sharing DS for all sorts of questions regarding Sam's doctors, teachers and milestones.

In short, Sharing Down Syndrome Arizona has made an ongoing impact in our lives for the past 17 1/2 years. We would have been fumbling along and instead, we were introduced to a wonderful community of love and caring. There are no words for what Sharing has done for our family. Samantha is not just her diagnosis. She is a model, an athlete, a Special Olympics Digital Ambassador and a really good human.

Love,

Jamie, Therese, and McKenzie
Samantha's biggest fans



NOT YOUR ORDINARY SAM!

We wanted to congratulate our very own Samantha Derivan. Sam will be featured in a display at Times Square in New York City. Samantha is an outstanding Colt and her efforts to promote inclusion for those with Down Syndrome speaks to the very core of our Casteel beliefs of Courage, Character, Commitment, and Compassion. Samantha is a member of our Unified Sports Program. She is one of those students that makes you smile when you cross her path on campus. Congratulations Samantha we are so proud of you!



More From Our Families...



"We are so grateful with Sharing Down and with our friend Gina Johnson; we met her in the NICU on 2018 when our baby Jeremy (we called him JJ) was recovering from 2 big majors medical interventions. Gina was the light in those difficult times.

Since then we love being a part of this wonderful community with awesome celebrations like Easter, Christmas and others, always under the wing of a huge smile and a big hug from Gina and the other people working with her.

*We are so grateful to be part of this wonderful family. And always is a pleasure to see Sharing Down people and specially Gina. Thank you for all you do for us." - **Marisol Gomez***

"Eleven years ago, our son was born six weeks prematurely. A week later, we found out he had Down syndrome. To be honest, on top of everything we had gone through with his pregnancy and birth, that was the last thing I wanted to hear.

The social worker in the NICU offered us support. She also told us about Sharing Down Syndrome AZ, and asked if she could contact them for us. We agreed. Gina came to the hospital to see us, bearing gifts and her characteristic smile. She never once said, 'I'm sorry' - as some had. She told us stories and offered us a shoulder; she beamed over Joshua as any proud family member would.

Gina and SDSA came to be somewhat of a rock for me during the first few years of navigating therapies, hospitalizations and that horrible self doubt."

- Debbie Fults



"When our son John Robert was born, my wife and I had no direction, no information, no support, no anything.

The morning Gina came to meet us and John Robert changed our lives forever! I remember Gina walking into our room and you would have thought we won the lottery. Gina was over the top excited not only meet us, but meet our son, John Robert. How could someone be so excited about someone giving birth to a child with Down Syndrome? Gina took lots of pictures gave us gifts, a new parent package and showed us so much love and support for our new baby and I was blown away!

Our son John Robert is now 11 and we have continued to support Sharing Down Syndrome throughout the years. I became the Chapter Leader for the dad's group - although things have been put on hold since the pandemic hit - but we always try and support every event put on by Sharing Down Syndrome Arizona because of Gina and the staff at Sharing Down Syndrome Arizona.

*John Robert is involved in so many sports and other activities it's hard to keep up - Sharing Down Syndrome Arizona is one of the greatest organizations I've ever been a part and proud to say I help volunteer when I can." - **Greg Marcell***



"I would like to express my sincere gratitude. Our family has had many challenges throughout this pandemic, especially trying to stay afloat keeping food on the table and being able to meet bills each month.

The grant that Sharing Down Syndrome AZ wrote for us to the Global Down Syndrome Foundation helped in so many ways. We were able to put groceries in our home and keep our lights on. My children and I are forever grateful for your generosity. Thank you so much!"

-Denitra Brent

"I moved to Arizona almost three years ago with my then 15 year old son, Brett, who has Down syndrome. We did not know anybody in the state with Down syndrome and we were very nervous since we were so close and connected with our Down syndrome community in our previous state. Our pediatrician first told us about Gina and Sharing Down syndrome Arizona and I took a chance and reached out.

Gina made efforts to get to know my son, our story, and made us feel welcome to the state and to our area. She connected us with resources and has provided advice to us as we've navigated entering adulthood for my son. She continues to advocate for the lives and needs of those with Down syndrome, and Gina is the most kind, caring, and empathetic person I've met. She truly has such a heart for our kids and their families, and having her connection on a personal level is something that we haven't experienced as much with other Down syndrome organizations.

We have had a difficult time with my son due to his rare diagnosis of **Lennox-Gastaut Syndrome (severe epilepsy)** in addition to Down syndrome. Gina was able to connect us with another mom of a boy his age who also has both diagnoses and receiving that support meant so much to me. It is a path that I previously have had to navigate alone because it is a rare diagnosis, and even more rare in Down syndrome. I am truly thankful for the ability of SDSA to exist and provide support and guidance to families in that way."

- Jennifer Nelson and Brett Logan (now 18 years old)



"We have a son Jacob, who is 26 and has Down Syndrome. Over the years SDSA has helped our family so much. It was always our goal to have Jacob attend public school, to be fully inclusive and receive a regular education that he was entitled to. Unfortunately, it wasn't always easy. SDSA was so helpful in putting us in touch with educated advocates that were there to aide us in getting the education that Jacob deserved and was right by our side at numerous IEP's, meetings and evaluations.

Without SDSA advocacy and advice, the road would have been a lot tougher. Jacob was able to experience sports, proms, award ceremonies, football games, pep rallies - right along with his peers.

He made friends that we believe will be life-long and special memories made. We are and will always be grateful to SDSA for all the support over the years, they are always there, always answering your calls. One of Jacob's favorite days of the year is the Sharing Down Syndrome Walk day - it's all about him and he loves it. And we love Gina Johnson and all of her people!"

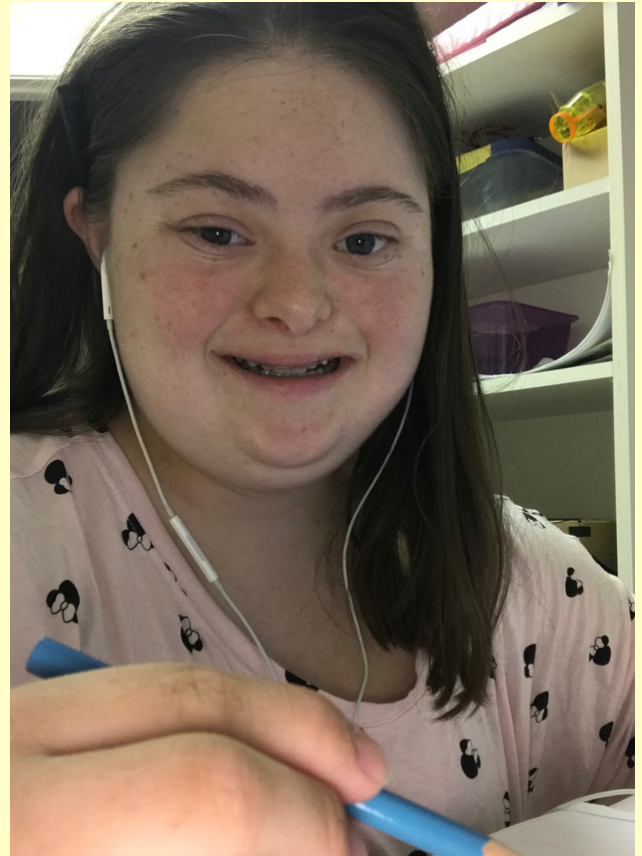
- Christie Schmidt

"We love the Sharing Down Syndrome - AZ organization! It has been a huge help in our lives as we have navigated the world of Down syndrome. From the moment we brought Danielle home from the hospital back in March of 2003, Sharing has been a part of our lives. You were one of our first visitors (outside of family) after Danielle was born and brought such a message of hope and excitement for our new adventures.

We have participated in all of the activities that your organization has offered - Yes, you are a great support for the Down syndrome community, but also to others in the disability world!

You helped us as a family gain the knowledge and courage to forge ahead in a world of uncertainty when we first joined the Down syndrome community and we could NOT have navigated it half as well without your organization."

-The Hulets: Jay, Kim, Katelyn, Brittney and Danielle



"We have been truly blessed with help from your organization ...even through Covid.

You have a wonderful staff. This year, we were blessed with a donation from your organization to help cover living costs, which was an amazing gift because I had to take leave from work (because of four kids doing school virtually), and my husband's work hours were cut.

So, from the bottom of my heart, thank you...THANK YOU! I wish there was more I could do, just know that you are greatly appreciated!"

-The Williams Family

"...A lot of people still say 'sorry' when they hear a woman will be delivering a child with Down Syndrome. Instead, Gina and her organization say 'congratulations' and celebrate this wonderful blessing.

Sharing Down Syndrome is a unique and necessary program and I am so thankful we found each other."

- Denise Ford, (son Malakai)





"From the moment we found out that our child was probably going to have Down Syndrome, the worries began. Not the worries about him not being a normal child, but the worries about how others would treat him. Little did we know how much of a waste of time and energy that would be.

Sharing Down Syndrome's founder, Gina, walked into our hospital room and shared her energy, understanding, and positivity. She gave us resources and knowledge which built our confidence. The organization gave us connection, support, pride, and hope. We walked out of the hospital with an abundance of nervousness, but confident we could be great with the help of family, friends, and the guidance and support of Sharing Down Syndrome AZ.

We developed the knowledge and courage to pay it forward to other families needing the encouragement and hope, because of what this organization has done for us. We are forever grateful and will always find ways to support Sharing Down Syndrome AZ."

-Crystal, Vance, and Ariston Danzy

"In 2019, our grandson Malek was born in Nagoya, Japan to my son and his wife. We, the grandparents, live in Phoenix, AZ. I traveled to Japan, stayed for 8 weeks to help out; Malek has an older brother and sister too!

Upon my return home, I had a huge package waiting for me from Gina's nonprofit. My husband and I opened it and were in awe of the educational material in it, books, articles, as well as fun stuff, a DS T shirt, etc.

This opened the door for us to Gina's wonderful organization. What a world of information at our fingertips to share with my son and his wife about babies with Down syndrome! I mailed some of the stuff to Japan after we read it all.

I look at SDSA's FaceBook posts and newsletters regularly. We do not feel alone. We will forever be grateful and continue to be involved locally!"

- Janice Morrison

