

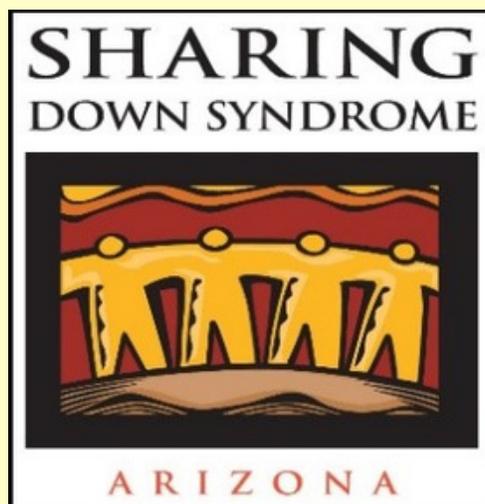
“The things that make me different  
are the things that make me.”

- Winnie-the-Pooh by A.A Milne



**Sharing Down Syndrome Arizona  
2022 Annual Report**

**Our Impact on the People & Community We Serve**



# From My Heart To Yours

## Love, David's Mom

Ever since I founded "Sharing" (in 1991), I have done all in my power to create a nonprofit that served families and at no cost to them. I wanted to make the path easier for those who follow, and I know we have achieved this goal and we continue to do so.

I do what I do because I love these children with all my heart. I know that life is not perfect and that there are challenges along the way; we parents see our children for the incredible people they are.

As I reflect on my work and life, I realize three important lessons by being 'David's Mom'.

1. The first lesson I learned is about the world; I know our world is a better place, simply because our children with Down syndrome are here.
2. The second lesson is about myself; when I look back on my life, I can see the person I've become simply because God trusted me enough to let me be 'David's Mom'.
3. The third lesson is about families and in particular siblings. I can see the powerful impact that our children with Down syndrome have on their siblings. I see it with my own seven children, and I see it each time I see your children. Without a doubt, most siblings who love a brother or sister with Down syndrome often display the moral courage to stand up for what is right and make a difference for good in the world.

I know that no matter where you live or who you are, our children with Down syndrome teach us to love and accept all people. They see the goodness in others. They make me want to have the same unconditional love they have.

Happy New Year to all of you, dear friends. Thank you for all you do for your children, your families and our community.

Love,  
Gina Johnson  
David's Mom



# Mission Statement, Board of Directors & Advisors

**Our Mission:** To champion and celebrate ALL people who have Down syndrome throughout the lifespan. To achieve our mission, we have the support of a Board of Directors and Board of Advisors to lead us in our efforts.

**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; Kevin Huff, Business Contributor.

**2021-22 Board of Advisors:** Jennie Bradfield, Dave Case, Adam Dixon, Keith Killourie, Sheri Reed, Sylvia Ricks, Barbara Wilkins, Nick Kowalski, Lynn Ferron and Allan Earl.

*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. Pictured below are some candid photos of some of our Board of Directors and Advisors from meetings in 2022.*



Jennie Bradfield  
& Gina Johnson



Sylvia Ricks  
& Gina Johnson



Leon Ricks  
BOD Vice Pres



Lynn Ferron  
& Gina Johnson



Chris Claridge  
BOD Treasurer



Gina Barreras, BOD  
Medical Contributor

# Angels Among Us Program

## Advocacy, Hospital and Home Visits



Antonio and his Proud Parents



Gina getting in a hug with Lilly

Number of hospital/home visits to new parents of a child with DS: 41

Provided educational advocacy services through Susan Marks & Advocates in the amount of \$1,836.50 in 2022

Distributed more than 85 hospital folders to area hospitals

*New in 2022: Added our Parent Packets online for free downloads in English and Spanish*

*Hired a Spanish Chapter Leader to reach more of our Spanish speaking families*



Hello there, Elijah

# Impacting Future Leaders through efforts with Arizona State University and The Alix School of Medicine - Mayo Clinic

Sharing Down Syndrome AZ (SDSA) was one of a select group chosen by The Global DS Foundation to receive a grant for our work at The Mayo Medical School in Scottsdale and at Arizona State University at the ASU Sensorimotor Lab (Dr. Shannon Ringenbach and her students.)

SDSA participates in studies at ASU and participates at special speaking events at ASU and Mayo throughout the year. We have been doing so for several years. These events give students an insight into what Down syndrome is all about, shattering old myths and stereotypes. In addition, many of our friends with Down syndrome also volunteer time at ASU to further advance groundbreaking research on Down syndrome.

This grant will cover the costs of these efforts, with the goal of making studies like the ones at ASU become part of a national curriculum. Below is one of the reflection papers written by one of the students.



*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. It was such a pleasure to meet you and I am so thankful that you took time out of your morning to speak with us. **What you all said was so important for us to hear and being able to witness Parker and Eric's infectious joy was just fun!***

*Most importantly, the message conveyed by Kay and Barb was incredibly uplifting for me personally. It really brought to mind the truth that all people are created equal and that all of us are worthy of equal dignity and respect. **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 Verhey (medical student at Mayo Clinic Alix School of Medicine)***

# SDSA sponsored events: A collage of people we served this year through events



Meet & Greet for WDS



Sharing Walk 2022



Sharing Walk 2022



Sharing Walk 2022



Sharing Walk 2022



Annual Christmas Party



Meet & Greet for WDS



Annual Christmas Party



Sharing Walk 2022

# Program Budget Overview



## Parent Visits & Advocacy

Our team sent gifts and resources to **41** 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**.

### Breakdown of costs for Parent Visits & Advocacy in 2022

- Mailing and shipping costs came in at approximately \$425.
- 41 new families served in the area @ \$125 is \$5,125.
- Merchandise expenses promoting DS awareness were \$1,068.
- Labor costs associated with this effort include a monthly car allowance of \$500/month or \$6,000 annually, plus the personnel costs of \$19,000.
- Labor costs for administrative personnel for database maintenance are \$2,160 annually.
- Educational advocacy was \$1,837 in 2022.

**Total program cost for Parent Visits in 2022 was approximately \$35,615**

## Communications & Outreach with our Community

SDSA staff produced a **monthly newsletter** (in English and Spanish) to communicate with parents. We email more than **3,000** people our newsletter each month. We hired a Spanish Chapter Leader to directly contact our Spanish-speaking families.

### Breakdown of costs for Communications and Outreach

- Constant Contact email annual fee is \$860.
- Webmaster expenses are \$3,600 annually.
- Website maintenance, upgrades and accessories cost approximately \$800 per year.
- Subscriptions to Adobe, Zoom are approximately \$30 month or \$600 annually.
- A bulk mail post card for end of an end of year giving campaign was \$2,998.
- Labor costs associated with Spanish Chapter Leader are \$1,800 annually.
- Other labor costs (personnel) associated with marketing are approximately \$15,500.

**Total program cost for communications & outreach in 2022 was approximately \$26,158.**

# Program Budget Overview (continued)

## SDSA Events

The SDSA staff, Board members, and volunteers hosted three (3) major events in 2022: The Gilbert Water Tower Lighting event for World Down Syndrome Day, The Sharing Walk for Down Syndrome, and the Christmas Party.

### Breakdown of costs for SDSA sponsored events

- Labor costs associated with this effort include the personnel costs of \$30,000 annually.
- Event costs in 2022 was \$25,160 for the Sharing Walk, and \$1,522 for the Christmas party. The Gilbert Water Tower Lighting was free and cost nothing except labor for SDSA staff, estimated at \$200. Event costs for these events included fees for the venues, insurance, entertainment, tent and table rentals, inflatables rentals, prizes for fundraising winners, signage, truck rental, games and balloons.

**Total program costs for (3) major events in 2022 was approximately \$57,000.**



# Community Resources & Events

Our organization informs our families about opportunities for their loved ones with Down syndrome. Each month, we connect with a newsletter and we post regularly on our social media channels and website about available resources. Below are some programs and resources we helped promote in our community:

- We promoted a **flag football team** that continues to flourish since 2021.
- 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, social media and our website.
- We promoted a **Spring Dance** 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.
- We created more **resources on our website** for parents and caregivers to get help with **guardianship, counseling and mental health services and Spanish resources**.
- We promoted **SuperFest** - a Super Bowl weekend experience, as well as **Ballet Arizona's adaptive dance program**, and **A/R Inclusion** teen and adult programs. We promoted a special needs basketball **Hoop Camp** and a **golf clinic and tournament**.
- We hosted a **Dessert Night, a Reading Time with Jackie gathering and Walking Group** in 2022 for families to connect in a smaller group setting.
- Along with the Greater Phoenix Autism Society, we joined the Chandler Police Department with a **Pizza with Police** event in October.



Pizza with the Chandler Police - Oct 2022



Spring Dance - March 2022

# Events & Fundraising



We coordinated the '**Super Hero Experience**' through the Colten Cowell Foundation for **7 families** between Jan-Dec 2022. Families and friends experienced Batman's headquarters, having a very special evening of fun and giving. The honoree gives a check for \$1,000 to SDSA and \$1,000 for another charity of his or her choice.

Our **Sharing Walk for Down syndrome** was held on April 23, 2022 at Tempe Diablo Stadium. More than **1,000** people participated in the event.

Team Mighty Quinn was our Top Fundraising Team for 2022. Quinn and her team raised over **\$3,000!** Team Liam was our second place winner, and Team Matias came in at third place.

We cannot thank all of the people who created a team, and supported (donated to) a team this year. Team fundraising efforts helped us to raise more than **\$25,000** for our organization.

Sponsorships raised another **\$23,900** and on-site/miscellaneous donations raised **\$4,444.**

The total amount raised for the Sharing Walk for Down syndrome was **\$53,618.** After expenses, the event raised more than **\$28,000** for SDSA.



# Other Fundraising

Sharing Down Syndrome Arizona is a registered **Amazon Smile** Charity and part of the **Fry's Community Rewards Program**. Your donations through **AmazonSmile** amounted to \$2,280. Your donations through the **Fry's Community Rewards program** amounted to \$1,500.



We mailed out our **Giving Tuesday** 2022 post card to over 7,000 people in early October 2022. The post card explained the Arizona tax benefit for individuals and families. **SDSA raised \$4,200**, with more donations that came in after November 29 for the Giving Tuesday campaign.

For **Arizona Gives Day** in April 2022, SDSA raised **\$2,580**.

Many other employee giving programs donated including **CharityAid, Benevity, Network for Good, American Express Foundation, The Home Depot Foundation, Honeywell Giving Foundation, Cuisson International, Panorama Global Fund,** and more.



**This Thursday  
Nov. 17th  
ALL DAY, ALL 3 SHOPS**

**ALL PROCEEDS will go directly to the Sharing Down Syndrome Organization!**  
"Educating, Empowering & Supporting people with Down Syndrome."



**Together as #SodaRushers we can help make a difference for so many families!**

**@SodaRushAZ**

**#SodaRushGivesBack**

**SodaRush** named SDSA a **Thankful Thursday** recipient of their fundraising efforts on Nov. 17th, 2022. On that day, all 3 shops donated the proceeds to our organization and presented us with a check for **\$500**.



## End of Year Giving Reminder

Take advantage of the tax credit up to \$800/couple or \$400/person.

We are a Qualifying Charitable Organization (QCO) in Arizona - so what you give, is what you get back on your taxes.

These tax credits allow taxpayers to make charitable contributions and receive dollar-for-dollar reductions in their Arizona state tax liabilities.

Our QCO Code is 20543.

[www.sharingds.org/donate](http://www.sharingds.org/donate)



# Major Funding Sources (donations over \$5k) and Financial Snapshot for 2022

SDSA received grants amounting in funding of **\$37,586** from the *Global Down Syndrome Foundation for \$6,400, The Saguaros (formerly the Scottsdale 20/30 Club) for \$10,000, The Colten Cowell Foundation for \$10,000, Albertson's Companies Foundation for \$5,000, and a \$2,500 grant from the Tempe Diablos*. Pictured below are the logos of our major donors (\$5k or more) in 2022.

*Corporate Giving and Employee Giving Programs* helped raise over **\$78,684** for 2022 - including a very generous donation from *Blacker Orthodontics of \$20,967*; in addition, their office team and clients coordinated and donated a toy drive to give all children a present at our Christmas party. SDSA was also gifted with a generous donation of *\$35,000 from a new donor, the No Missing Links Foundation*. Other major corporate donations in 2022 came from *Kerr Endodontics (\$5,000) and Providence Homes (\$10,000)*.

*Individual general donations* raised **\$33,275** for 2022.

*Earnhardt Auto Centers employees* donated **\$6,547** to SDSA in January 2022. *SRP employees* donated over **\$2,200** in 2022.

## 2022 Financial Information at a glance

- Total estimated expenses for 2022: \$165,377
- Total estimated income: \$213,437
- Estimated Profit: \$48,059

*Note: tax information (990s for 2022) will have exact amounts once completed by mid-May 2023.*



**No Missing Links Foundation**

# Thank you Sponsors & Exhibitors

Here is a list of sponsors of our 2022 Sharing Walk for Down syndrome held on April 23, 2022.



## **Diamond Sponsors:**

Blacker Orthodontics  
Providence Homes  
Scottsdale 20/30 Club

## **Platinum Sponsors:**

Earnhardt Automotive Employees  
The Colten Cowell Foundation  
Kerr Endodontics

## **Gold Sponsors:**

Farnsworth Ricks Management & Realty  
Phelps LeClair Estate Law  
All Aboard Services  
Johnson-Larsen Family Dentistry

## **Silver Sponsors:**

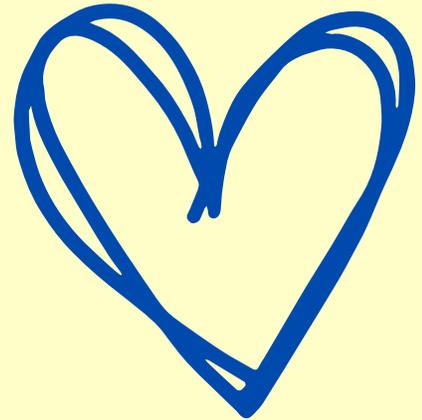
Paul Kelly Maxillofacial  
The Tempe Diablos  
Valle Luna Mexican Food & Cantinas  
Save This Memory Photography & Videography  
Integrate (Software company)  
Salt River Project Employees  
Usborne Books - Jackie Killourie  
Vindicor Pest Services  
Sassy's Cafe & Bakery

## **Bronze Sponsors:**

Arizona for Better Medicaid  
Milestone Pediatrics  
Endeavor HCBS  
Aloha Desert Pools  
Best Trophies and Awards  
Basha's Supermarkets  
Sprouts Farmers Market

## **Friends of Sharing - Special Exhibitors:**

Hospice of the Valley (Dementia Care)  
AZ Dept of Economic Security - Department of Developmental Disabilities  
TheraCare Pediatric Services  
Ballet of Arizona - Adaptive Dance program  
Susan Marks & Advocates  
Chroma CuteTees  
Raising Special Kids  
Sharing Down Syndrome AZ - Spanish Chapter  
KinectAbility  
ASU Sensorimotor Research Lab



# How We Reach Our Families

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 2022 and we have **4,675 followers**. 79% are women and 17% are men. This is the most effective social media channel for SDSA to reach our followers.

**Twitter** – SDSA followers increased from October 2020 to **279 followers** to **336 followers** in December 2022.

**Instagram** – SDSA followers grew from **1,166 followers** in November 2021 to **1,300 followers** in December 2022.

In **Constant Contact**, we have **3,071 email subscribers**, many of whom receive monthly newsletters from the list Proud Parents (English & Spanish). Our open rate for the December 2022 newsletter was up from 31% in 2021 to 41% (*3% above the industry average*).

We have **4,004 families** in our customized database as of 12/31/2022 and **7,313 total people** (all mailing list) in our customized database.



**Sharing Down Syndrome Arizona**  
Published by Gina Campbell Johnson [?] · ★ Favorites · August 31, 2022 ·

Cuteness overload for the day. ❤️

**Performance for your post**

**9,784** People Reached

**565** Reactions, Comments & Shares

<b>272</b> Like	<b>30</b> On Post	<b>242</b> On Shares
<b>233</b> Love	<b>51</b> On Post	<b>182</b> On Shares
<b>38</b> Comments	<b>3</b> On Post	<b>35</b> On Shares
<b>23</b> Shares	<b>23</b> On Post	<b>0</b> On Shares

**129** Post Clicks

<b>33</b> Photo views	<b>0</b> Link clicks	<b>96</b> Other clicks
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**NEGATIVE FEEDBACK**

<b>4</b> Hide post	<b>5</b> Hide all posts
<b>0</b> Report as spam	<b>0</b> Unlike Page

Reported stats may be delayed from what appears on posts



**Our most popular post of 2022; we reached 9.8k people**

# Our efforts for being eco-friendly in 2022-2023

## SUSTAINABILITY



### Organizational Initiatives

Provide recycling receptacles at all large public events and reduce waste

Reduce the amount of helium balloons at events

Use reusable bags instead of plastic bags

Make fewer paper copies (use less paper) and make communications mostly digital- use both sides of paper whenever possible

Create a work schedule where commuting is done only 3-4 days per week; offer remote work

Carpool when possible

# From Proud Parents...

*I want you to know how special you are to our family. From the moment Katie was born and 17 years later, Sharing Down Syndrome has been a comfort to us.*

*There is not a day goes by that we thank God for our blessing of our beautiful daughter Katie! Attached is a recent picture of her. We have thousands ♥...*

**-Shirley Seay**

*Let me tell you my experience with Sharing Down Syndrome. When little Franklin was born, we were so clueless and mixed up. My wife was visited by Gina, and had a wonderful experience learning about DS. The reassurance that she brought, meant so so much, at a time when nothing was sure.*

*This past month, SDSA provided a paid consultation with an expert, with tons of ideas of how to navigate the therapy/kindergarten/parenting balancing act. We will be now empowered to do one of three different options in each of coming years.*

**-Dan (RaeLyn) Whiter**



*I cannot thank you guys enough! Joshua had the time of his life (at the SuperHero experience) and everyone went away with lifelong memories and will remember this experience forever. My granddaughter said, 'Me-maw, I wish I had Down syndrome. Uncle Josh gets to do everything cool.'*

*I am very honored and humbled that you picked Joshua and let our family experience this; not to mention Dad has not stopped talking about driving the bat mobile. Thank each and everyone that had a part in making this so special for everyone. **-Sherrie Wittrig***

# SDSA strategic initiatives for 2023

## Technological advances:

SDSA is currently working with our webmaster to improve our website functionality, including making our website accessible for those with disabilities. We will also soon be offering multi-language translation features. These efforts will increase our inclusivity in our community. In 2022, we made improvements to our website content adding sections on **innovative employment opportunities, guardianship, and mental health support.**

We have also made our **hospital folders downloadable on our website (in English and Spanish)** so we can **reach more families in rural areas and beyond.** We will continue to look for ways to always be as inclusive as possible using the most current technological advances.

## Advisory Board Member Outreach:

SDSA is always looking for and accepting new people to join our advisory board. Our goal is to reach more people from different backgrounds, with an emphasis on diversity and a commitment to people with Down syndrome. If you want to be a part of the advisory board, please email **angie@sharingds.org.** People with disabilities (especially Down syndrome) are highly encouraged to be a part of our advisory board.

## Investment in our communities:

We have pledged \$500 annually for the next five (5) years to the Global Down Syndrome Foundation for **advancing medical research** for people with Down syndrome. We will continue our **ambassador program at ASU and Mayo Clinic** reaching new medical professionals and helping to change the paradigm about Down syndrome for the future. We are also supporting a **Prescott and surrounding areas chapter** (Northern Arizona) of SDSA in 2023 and will continue to work with people all around Arizona and Navajo Nation to communicate resources and opportunities online and when possible, in person.



Hospital folders downloadable on our website in English & Spanish



Website now has links to Early Intervention, Mental Health support, Guardianship info, more

## *MAKING A DIFFERENCE*

*One day a man was walking along the beach when he noticed a boy picking something up and gently throwing it into the ocean. Approaching the boy, he asked, "What are you doing?" The youth replied, "Throwing starfish back into the ocean. The surf is up and the tide is going out. If I don't throw them back, they'll die."*

*"Son," the man said, "don't you realize there are miles and miles of beach and thousands of starfish?"  
"You can't make a difference!"*

*After listening politely, the boy bent down, picked up another starfish, and threw it back into the surf. Then, smiling at the man, he said.....  
"I made a difference for that one."*

*-Loren Eiseley*

