



Sharing News



Volume 5, Issue 6

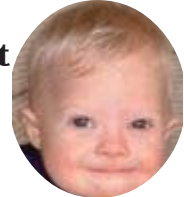
1

June 2004



"I know God will not give me more than I can bear, I just wish he didn't trust me so much."

Mother Teresa



Contents

In this issue:

Happy Father's Day..1

Contact Information..2

Announcements.....2

In the Spotlight.....3

In Loving Memory....4

From My Heart to Yours.....5-6

Luau Thank You.....7

Anuncios.....8

De mi Corazon al Corazon de Usted..9-11

A dad is someone who has pictures in his wallet where his money used to be.

Author Unknown

To become a father is not difficult, but to be a father is.

Author Unknown



My father didn't tell me how to live;

He lived, and let me watch him do it.

Clarence B. Kelland 1881 -1964



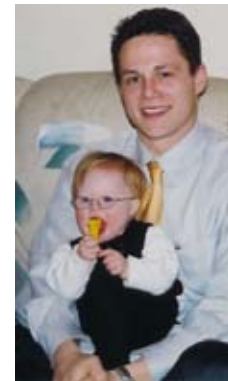
When I was a boy of fourteen, my father was so ignorant I could hardly stand to have the old man

around. But when I got to be twenty-one, I was astonished at how much the old man had learned in seven years.

Mark Twain 1835 - 1910



We here at Sharing would like to express our love and gratitude to all your dear dads who love your children!



745 N. Gilbert Rd. #124
PMB #273
Gilbert, AZ 85234
(480) 926-6500
President: Gina Johnson
gina@sharingds.org
www.sharingds.org

Happy FATHER'S DAY!

Sharing Down Syndrome Arizona! Mission Statement

Sharing Down Syndrome Arizona (SDSA) provides an uplifting place where parents, families, and community can share the joys and unique challenges of loving a person with Down syndrome (DS). Education and personal experiences are offered in various forums to help empower families and service providers. SDSA is unique in that it changes how society views people with DS. Once a person is introduced to others involved with SDSA, he or she will be changed forever. Celebration eclipses initial feelings of regret and depression; in time most feel blessed by their circumstances. The primary goal of SDSA is to integrate people with DS into society in order to establish a well-balanced community. All those who develop relationships with people with DS are better off because of it.

Newsletter deadline is the 10th of each month for publication the following month.

Website: www.sharingds.org

You can:

- Submit photos of your child
- Submit a spotlight
- Ask or respond to questions with other parents
- Make a donation
- Read articles and poems
- See upcoming events
- Read past newsletters

SDSA Advisory Board Members

President-Gina Johnson (602) 622-6344,
gina@sharingds.org

Vice President/Secretary-Theresa Gloria-Cervantes
(480) 980-3515, theresa@sharingds.org

Treasurer-Kay Bradshaw, kaygb@juno.com

Newsletter Editors/Webmasters-Jared and Tara Phelps
(480) 888-9913, newsletter@sharingds.org

Photographer-Perry Sevey, www.seveyvideo.com

"STARS" - DeAnn Hansen, deann@greenaspen.com

Good Grief Meeting Hosts-Kevin and Shawnie Huff
(480) 988-0434, khuff.family@cox.net

Teen Plus Coordinator-Liz Perez (480) 755-7231,
elizabethr@mail.de.state.az.us

Todos Los Ninos Son Especiales Coordinator-Raquel Hoffman (480) 987-8218, raquel_hoffman@msn.com

Additional Advisory Board Members...

Curtis Johnson - molarman.j@juno.com

Stacy Tetschner - stacy@nsaspeaker.org

Dr. Dudley Halpe - dudleyh@earthlink.net

Tom Baird - tomb@creativeenvironments.com

Bill Grogan

NEW BABIES

Proud Family: Kim Moore and Family
Alex Moore, born March 34, 2004

Proud Parents: Donna and Robin Linsk
Hannah Grace Linsk, born April 24, 2004

Proud Family: Mindy Bejarano and Family
Tanner Matthew Bejarano, born February 20,
2004

Proud Mom: Deborah Gilbert
Blake Thomas Gilbert, born March 29, 2004

Proud Parents: Sonya and Israel Alvarez
Sophia Alvarez, born January 17, 2003

NEW FAMILIES

Proud Parents: Rich and Janette Thompson
Mia Angelica Thompson, born March 14, 2002

Proud Mom: Michelle Morgan
Kaitlyn Leanne Morgan, born February 17, 1998

Proud Parents: Esteban and Maria Valdez
Juan Pablo Valdez, born January 18, 2003

Proud Mom: Kimberly Harbottle
Kristyn Elizabeth Harbottle, born April 2, 2003

Buddy Walk Silent Auction Items Needed

We are collecting donated items for the Buddy Walk raffle and silent auction. If each of you can ask one business that you frequent, we can collect everything to earn the funds to support the families throughout the year! Please contact Tanya Clark if you collect anything, or if you need anything, such as a letter on SDSA letterhead to pick up the donation.

**Tanya - 623-536-4804 (hm) or 602-418-2113 (cl) or
email yogatanya@msn.com**

Calendar of Events

July 22, 2004 to July 25, 2004, All Days: National Down Syndrome Conference

We have attended these uplifting and motivational events! We even meet families from around the nation and world. Take time to visit the web sites of these two conference and see what is being offered this year.

The National Down Syndrome Conference takes place July 22-25 at the J.W. Marriott Hotel , Washington D.C. There are 4 ways to register:

Mail: NDSS Conference Registration, 506A Main Street, Boonton, NJ 07005

Call: 800.317.7554

Fax: 973.556.1912

www.ndss.org

August 20, 2004 to August 22, 2004, All Days: National Down Syndrome Congress National Convention

Whatever the age of your family member or student with Down syndrome, you are sure to find terrific opportunities for learning and networking at the NDSC's 32nd annual convention, the largest gathering devoted to DS in the United States. You will hear well-known professionals, self-advocates and parents address important issues across the life span. Friday's schedule includes several one-time events: pre-conferences, a film festival; separate sharing sessions for moms, dads, and grandparents; Self-Advocates in the National Spotlight; and the opening reception and silent auction.

Saturday and Sunday feature over 30 workshops, 3 general sessions, and the Awards Banquet.

The Youth/Adult Conference for self-advocates ages 15 and older and the Brothers/ Sisters Conference for siblings ages 12-18 begin Friday afternoon with get-acquainted activities and continue on Saturday and Sunday. We hope you are making plans now to join us August 20-22!

Minneapolis, Minnesota at the Hyatt Regency 612-370-1234 or 800-233-1234. Room rates : \$110 + tax per night, single or double. Registration deadlines - July 12 for brothers/sisters, youth/adult, and pre-conferences. July 31- general convention. Don't miss the Y/A registration deadline of July 12!

Again this year the NDSC has kept family and individual registration at the same low price as last year. This terrific opportunity for learning and networking coupled with our affordable rate structure makes the NDSC Convention truly a "best buy!"

NDSC Members: \$85 Individual or \$150 Family

NDSC Non-members (Includes Membership Fee): \$115 Individual or \$180 Family

Ideas for possible scholarship sources are listed on the NDSC website at www.ndscenter.org

October 23, 2004, 8:00am: Annual Buddy Walk

Join us at Pera Park for a fun day! To join the committee, call the Sharing office at 480-926-6500.

March 19, 2005, All Day: Abby's Angel Ride

Join us for the Third Annual Abby's Angel Ride sponsored by Valle Luna. We will have a motorcycle ride, lunch, T-shirts, etc. Mark your calendars!

Scrapbook Corner

PLEASE complete a scrapbook page for the SDSA album. We want to have a little piece of each family in our memory book!

Contact Joy Story-Perkins for more information: 480-380-1117 or cropwithjoy@cablaz.com

In Loving Memory

Riley Hoyle

February 18, 1995 - June 27, 2001

In Loving Memory, Zachary Linn

March 15, 2003 - March 18, 2004

When Gina asked my husband and I to write a tribute to our beautiful son, Zachary, we were honored. What we didn't know is how hard it would be to put all of our feelings for Zach in words.

Zachary came into this world much too early. He and his twin sister, Emilie (no DS) were born at 25 weeks. My husband and I were crushed because the dream of our full term delivery had been shattered. We were so frightened and our biggest daily goal was to keep our children alive. From Day 1, Zachary was so strong and had such a will to survive. We now believe it was because he had a purpose and a goal to accomplish. Three weeks after the twins were born, we found out about Zach's Down's syndrome. Once again, my husband and I were crushed because our dream of having a "normal" baby boy had also been shattered. What we didn't realize at the time was that we were actually blessed with the most incredible little boy.



Without ever speaking one word during his short life, Zachary taught us more than years of schooling could teach us. He taught us the true meaning of unconditional love, he taught us that it's the small things in life that matter most, and he encouraged us to be closer to God. Overall, he made us better people and we'll always be grateful to him for that.

As time passed, our sweet little boy tried so hard to be strong. He required high levels of oxygen, ventilators during sicknesses, a feeding tube, apnea monitor, pulse oximeter and breathing treatments. In the end, a rare heart disease took his life. The special doctors and nurses at Scottsdale Shea NICU and Phoenix Children's PICU all loved Zach. He had home health nurses that cried as hard as we did when Zachary passed away. He had a way of touching everyone's heart. You couldn't help but just fall in love with him.



Zachary became our hero for all that he endured. As my husband and I lay with him in our arms the night he passed away, we just kept telling him over and over how much we loved him and how proud he made us. We also thanked him for all that he taught us and for changing our lives. We asked him to forgive any of our parenting pitfalls as we all have. We told him not to be scared and to finally go and enjoy his first true quality breath and to have fun running around heaven making everyone smile. We never said goodbye to Zachary,



only goodnight and that we would see him again soon.

During Zachary's funeral service, our dear sweet minister who has become such a blessing in our lives, honored Zach and all of our beautiful children with any type of disability with the following message:

"Normal" should be described as someone who gives and receives love. In that regard, Zachary was probably more "normal" than many.

So as we look back on our shattered dream of not having our "normal" little boy, we are convinced that Zachary was more than "normal", he was a blessing to us...a true Angel. He absolutely stole our hearts.

We miss our hero, butterfly and Angel baby boy. Goodnight Zachary, we'll see you again soon.

Love, Mommy and Daddy

From my heart to yours...

Dearest Beloved Friends,

There's a song that keeps going through my mind the lyrics of which sing, "What I did for love." I thought about that song on April 20th as Theresa Gloria-Cervantes (SDSA vice president) and I attend the Disability Rally at the State Capital. We saw so many parents and providers gather to let their voices be heard. I knew it was important to let the senators and legislators know how they felt about having services cut for their children or for the people they serve.



I was especially proud when Sharon Baird (proud mom of Chase), Margaret Finestone (proud mom of Benjamin) and even a cute proud grandma, with her beloved, stood up

to speak in the microphone to tell not only the love they had for their children but about the need for the services provided.

As I looked at these young mothers and proud grandma I realized how wonderful life is and that our world is in very good hands. How thankful I am for Bev



Hermon (a mother like us who also loves an older son with a disability) as she is faithful and valiant in not letting important issues go by the wayside with out informing us (PS If you want to be included on her disability listserve just write her at Ddadvocates@aol.com)

That day was special to me and then on Thursday April 29th, Theresa and I drove to the rural town of Maricopa to attend the funeral for one of the sweetest little boys I have ever known. His name was Nathan Cale Williamson. I met his mom Carmen when that little boys was just days old. I was impressed that she would contact me when he was so tiny. When we visited I couldn't even imagine what it would be like to



have two year-old twins and then a new baby who had Down syndrome, but she was so darling. As we spoke, I could feel such magnificent love in her voice for her newborn son and almost an excitement for the journey ahead.

Back then, there was no way she or her husband David could have ever imagined that this day would come a short two years and two days after his birth. I know it will sound weird for me to tell you that this baby's funeral was so beautiful but it truly was. You could feel the sweet spirit of love that filled the chapel of their Baptist church.

One of the best parts was when David and then Carmen stood to publicly thank God and express the gratitude they felt for the brief time Nathan had been allowed to stay. And they expressed to a most humble testimony of their love and faith in Jesus Christ. The day Carmen called to tell me Nathan had passed away I was in shock. He had not been ill so it took us all off guard. Instead of feeling anger - as I might have - she expressed, through her tears, her feelings, "I wasn't done loving him, I wasn't done teaching him, but his work was done." My heart was most humbled as this sweet broken-hearted mother accepted with a most humble heart God's will, both when He sent this precious son and when He called him home. I thought about the dedication these parents had to drive over 100 miles to faithfully attend our Sharing meetings.



One night at one of those meetings we were talking about what the future holds for our children. She cracked me up by saying, "There are only two things we won't let Nathan do - Ride a bucking bull and play football." I chuckled



*Angels Among Us
Nathan Cale Williamson
April 18, 2002-April 20,
2004*

but the look on her face told me she was not joking. She continued, "and the only reason we won't let him do those things, is his doctor said no because of his heart."

I glanced over at Nathan's proud dad, David, and could tell by the expression on his face that he too couldn't be prouder of his son. As I looked into the soft blue eyes of this proud daddy with his sun-tanned face I realized that this daddy had ridden bulls in his day and that given the chance for his son to do the same, he would have cheered him on.

A few days ago I was in my daughter Samantha's room and noticed a poster on the wall above her bed of the ski trails at Brighton Ski Resort in Utah. (Where the kids love spending their Spring breaks.) On that poster were printed the words, "Go Big or Go Home!"



Now not being a snowboarder myself, and having long since passed my teenage years where I actually understand their lingo I had no idea of what it meant. It was my older son Brad who once tried to explain it to me. In a way it's probably good that we parents don't know all the crazy things our teenagers do. Because some of those things entail things like wake-boarding and flipping in midair or

snowboarding and jumping on metal pipes and rails just for fun. But the scariest part for me is knowing my kids go off slopes as high as they can go to catch some air.

(Now you know why I prefer to stay at the bottom of the hill and take pictures.)

To a seasoned snowboarder, the phrase, "Go Big Or Go Home" is a statement of life being lived to the fullest. As I thought about that statement I realized this philosophy was the same that Nathan's parents were willing to let him live.

Carmen had mentioned that one of Nathan's favorite toy was a stuffed gorilla that would sing and bounce

around when the button was pushed. The song he sang was "Hooked on a Feeling." Her favorite part was that when the gorilla sang and danced, so did Nathan! For he was hooked on a feeling, as were his parents, and that feeling was life and love. We will miss you dearly dear little one. Thank you dear Carmen and David for sharing your son with us.

With all our love,
David's Mom (Gina Johnson) and all of the parents of
Sharing Down Syndrome Arizona



**thank
YOU** to all our
sponsors

Arizona Children's Surgery, PC
Creative Environments Design and Landscape
Developmental Education and Research
Environmental Response, Inc.
Curtis D. Johnson, DDS
W. Bradford and Pauli Perkinson

Sharing Hawaiian Luau a success! Mahalo!

Wow!!!! I am still in shock and still on cloud nine as I think back to the wonderful Hawaiian Luau that Stacy and Michelle Tetschner hosted for SHARING. Stacy and Michelle are the proud parents of three handsome sons, including adorable adopted Raymond, whom they've adore. I wanted to help with this event but Stacy insisted that Curt and I just come as guests. That night as we walked into the room, I thought my heart would burst with joy. The convention center was decorated palm trees and beautiful flowers and posters that reminded me of my favorite place on earth.

When we first arrived our friend Tom Baird came up to us saying, "There is something here that I know you will want, so you might as well get it over with and tell me how much you are going to bid because we are going to bid more!"

I had no idea what he was referring to, until I saw the most beautiful white bench covered with the handprints of so many of our children that I understood. He was right...I DID want it! But during the course of the evening the cost went up to \$500.00 so I knew it was out of my league. But I was excited for whoever did get it.

That night a lump was in my throat as I saw so many fantastic items donated and even more so as I saw all but a few seats filled with smiling faces. I knew some people, but many I did not. It made me cry that they would come to spend \$50.00 a plate for dinner and then, just for good measure, brought even more money so they could purchase the items that had been donated to us with love.

When Stacy first suggested at our board meeting that he wanted to do this for us, I was glad but yet nervous for him. We had never done anything like this before and I wasn't sure how it would turn out.

I am sure part of being the Executive Director of the National Speaker's Association requires one to have a positive attitude but this attitude is part of who Stacy is.

I worried just how do you ask people to spend \$50.00 a plate for dinner and then ask them spend even more on the awesome auction items? As time progressed only a handful of people had signed up and so I suggested to Theresa, SDSA vice president that we cancel the Luau so Stacy does not do all this work for nothing. I thought she would agree with me, but instead she looked at me and with conviction said, "Gina, where is your faith?!"

She was right...I had forgotten for a moment that I have always known the only way SHARING has ever been able to do anything is because God loves our children with all his heart and it has been He who has brought us to where we are these past 13 years. Once again He blessed us beyond measure.

As Stacy introduced me to say a few words about Sharing, I was surprised that for the first time in my life, I felt nervous. I looked around at the nearly 100 people who were there and realized there were so many I didn't know.

When I spoke I could not only tender tears of love in the eyes of those who were there, but I could feel such a powerful feeling of love that it made it hard for me to speak. As if the evening wasn't great enough, when the Hawaiian dancers got up to perform, their teacher shared with me that her brother, who still lives in Samoa, has Down syndrome. As she spoke of her love for him there was not a dry eye in the place.

In the Hawaiian language "Mahalo" means thank you. It is with all my heart I say "Mahalo" to Stacy, Michelle and his wonderful Executive Assistant, Audrey O'Neal, who did so much to make this event happen. And I especially want to say thank you to our sponsors and all those who came to party with us. You beloved people helped us raise over \$7,000.00 that night. Also in Hawaiian, the word for family is "Ohana." The literal translation means "no one is left behind."

Thank you dear families for teaching our world that we would never consider leaving our children who have Down syndrome behind. Through your devotion, your persistence and your love, you are changing society's attitude not only about our children, but about all people who have a disability. God bless you all.

MAHALO!

With all my love,

Gina

PS At the end of the evening Lisa Blair (proud mom of Hannah) presented the bench to me. She said her parents, Pauli and Brad Perkinson, along with their whole family wanted me to have it. I know that you're jealous but if you ever want to come and see it, just come over as it holds a place of honor in my entry way. THANK YOU!!!!!!!!!!!!!!!!!!!!

Wow!!!!! Sigo impresionada y pienso atraz de el magnifico momento de la fiesta de Hawaiiana que dio la anfritiones Stacy y Michelle para Sharing. Stacy y Michelle son los orgullosos padres de tres guapos hijos, incluyendo al adorable Raymond a quien adoptaron, quien no los adora a ellos. Yo queria a yudar en esto pero Stacy insistio que Curt y yo fueramos invitados. Esa noche a como nosotros caminabamos hacia el cuarto. Pense que mi corazon estallaria de felicidad, el lugar estaba decorado de unas lindas palmas y flores y posters que me recordaron mi favorito lugar de la tierra.

Cuando llegamos nuestro amigo Tom Baird llego asi nosotros y dijo "Hay algo aqui que yo se que tu quedras, entra y dime cual es tu oferta porque nosotros daremos mas!"

Yo no tenia idea a lo que el se referia , hasta que vi una banca para sentarse cubierta con las manos de algunos de nuestros ninos y ahi entendi. El esta correcto Yo la queria. Pero durante el trascurso de la tarde el costo de la banca subio hasta \$500.00 pues yo supe que estaba fuera de mi presupuesto. Pero estaba emocionada por quien la obtuviera.

Esa noche se me hizo un nudo en mi garganta cuando mire algunos fantasticos articulos donados. Yo conocia algunas personas, pero la mayoria no me hizo llorar que elgunos gastaron \$500.00 en el plato de cena y luego traer mas dinero solo para comprar algunos de los artuculos donados para nosotros con amor.

Cuando por primera vez Stacy nos sugerio a nuestro comite de juntas que el queria hacer esto para nosotros, yo estaba feliz pero nerviosa por el. Nosotros no habiamos echo algo asi antes y no estaba segura como saldria todo.

Yo estoy segura la parte para empezar a ser ejecutivo director nacional requiere tener una actitud positiva pero esta actitud es parte de lo que Stacy es.

Estaba preocupada tan solo por preguntarles a las personas en gastar \$500.00 en un plato de cena y no tan solo eso, preguntarles en gastar mas para nuestros artuculos de donacion? A como pasaba el tiempo solo algunas personas confirmaron para ir a la cena y yo le sugeri a Theresa, my vice precidenta que lo cancelamos la fiesta de Luau y Stacy no tendria que hacer todo este trabajo para nada. Pense que ella estaria de acuerdo conmigo, pero ella me miro y me dijo, Gina donde esta tu fe?"

Ella estaba correcta...yo olvide por un momento que siempre he sabido que el unico camino que Sharing que ha tenido la oportunidad de hacer algo es porque Dios ama a nuestros hijos con todo su corazon. Otra vez nos bendigo a nosotros.

A como Stacy me presento y me pidio que hablara acerca de Sharing. Yo estaba sorprendida, por primera vez en mi vida me senti nerviosa. Mire al rededor y vi a 100 persona quienes estaban ahi y pense que eran mucha gente que ni conocia.

Cuando empeze hablar solo tiernas lagrimas de amor quienes estaban ahi, pero podia sentir el poder de el amor, eso se me dificulto al hablar. Y esto no fue suficiente, cuando los bailarines de Hawaiianos estaban en la tarima, su maestra compartio conmigo que su hermano quien vive en Samoa, tiene syndrome de down, como ella me estana platicando su amor por el, no habia un ojo seco en ese lugar.

En el lenguaje Hawaiian "Mahalo" significa Gracias. Y con todo mi corazon dije gracias a Stacy, Michelle y su estupenda secretaria, quien hizo mucho para que este evento pasara. Y especialmente quiero decirles gracias a todos nuestros patrocinadores y a todos aquellos quienes fueron a la fiesta con nosotros, ustedes nos ayudaron a juntar solo esa noche mas de \$7,000.00. Tambien en Hawaiian la palabra para familia es "Ohana". En traduccion literal significa "nadie se queda atraz".

Gracias queridas familias por enseñarles al mundo que nosotros nunca dejaremos a nuestros hijos quienes tienen syndrome de down atraz. Por medio de su devocion, tu persisitencia y tu amor, tu estas cambiando a la sociedad en actitudes no solo acerca de nuestros hijos, acerca de todas las personas quienes tienen discapacidades.

Que Dios los bendiga a todos.

MAHALO!

Con todo mi amor,

Gina

PS al final de la tarde Lisa Blair (orgulloza mama de Hannah) me regalo la banca. Ella me dijo que sus padres, Pauli y Brad Perkinson y toda su familia querian que yo me quedara con la banca, yo se que tu estas celoso pero cuando deseas puedes venir a verla, solo ven, y esta en un lugar de honor en la entrada de mi casa. Gracias!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!

De mi Corazon al Corazon de Usted...

Queridos amigos,

Hay una cancion que viene a mi mente "Que es lo que hice por amor". Yo pense acerca de esa cancion el dia 20 de abril, Theresa Cervantes (mi vice presidenta) y yo atendimos a la manifestacion de discapacitados en el estado de el capitolio. Vimos a muchos padres y proveedores reunidos para que sus voces se escucharan. Yo sabia que era importante dejarles saber a los senadores y legisladores como ellos se sentian acerca de cortarles los servicios para sus ninos o para las personas que ellos sirven.

Yo estaba especialmente orgullosa de Sharon Baird (orgullosa mama de Chase), Margaret Finestone (Orgullosa mama de Benjamin) y tambien vi a orgullosas abuelitas. Paradas para hablar en el microfono para decir no solo en amor que ellas tienen por sus hijos pero acerca de la nesecidades por los servicios.



Como yo las miraba a esas dos jovenes madres y orgullosa abuelita, pense como la vida es tan estupenda en nuestro mundo esta en buenas manos. Como me siento agradecida por Bev Hermon (una madre como nosotros quien tambien ama a su hijo mayor con discapacidad). (Ps si tu quieres ser incluida en su lista de servicios de discapacidades solo ve y escríbele a Ddadvocates@aol.com.)

Ese dia fue especial para mi y despues Jueves 29 de abril, Theresa y yo manejamos al centro rural de el Maricopa para atender al funeral de unos de nuestros dulce ninos. Su nombre era Nathan Cale Williamson. Yo conoci a su madre Carmen cuando solo el tenia dias de nacido. Yo estaba impresionada porque ella me contacto cuando el estaba aun muy chiquito. Cuando la visitamos, no podria imaginar como era tener a unos gemelos de 2 anos y un recién nacido quien tenia el syndrome de down, pero ella fue muy querida. Como nosotros estabamos hablando, podia sentir un magnifico amor en su voz por su recién nacido hijo.

En ese tiempo no habia un camino que ellos podian imaginar que desde ese dia y su apenas 2 anos con 2 dias despues de su cumpleaños pasaria esto. Yo se que sonara extraño de mi por decirles que en el funeral de este bebe fue hermoso y la verdad lo fue. Ustedes podian sentir el dulce espiritu de el amor que lleno la iglesia bautista.

La mejor parte fue cuando David y Carmen se pararon enfrente de el publico para darle las gracias a Dios y expresarles su gartitud, ellos espresaron el mas lindo testimonio de amor y fe en Jesucristo. El dia que Carmen me hablo para darme la noticia de que Nathan habia muerto yo estaba en shock. Ella me espreso en llanto sus sentimientos "Yo no estaba lista para vivir sin el." Yo no termine de enseñarle, pero su trabajo ya estaba terminado"mi corazon sintio humildad de esta madre que se le quebro su corazon aceptando con humildad el designos de Dios. Pense en la dedicacion de estos padre tubieron solo por manejar 100 millas de una fe completa para atender a nuestras juntas.

Una noche de esas de unas de las juntas hablamos acerca de el futuro que le espera a nuestros hijos. Ella me sorprendio cuando dijo, "solo hay dos cosas que no le dejariamos hacer a Nathan, manejar bicicleta y jugar football" me sorprendi pero su mirada me dijo que ella no estaba jugando. Ella continuo, "y sola la razon que no le dejariamos que el haga esas cosas, es que su doctor dice que no por su condicion de su corazon."

Mire al orgullozo papa de Nathan, David y podria saber por su exprecion en su cara porque no el no podria estar orgullozo de su hijo. A como yo lo miraba en sus ojos azules a este orgullozo padre. pense que este padre monto un toro en sus tiempos y eso le daba la oportunidad para que su hijo pudiera ser lo mismo, el tendria que compartir eso con el.

Unos dias atraz yo estaba en el cuarto de mi hija Samantha y mire un poster en su cuarto en la pared arriba de su cama de la pista de esqui de Brighton Ski Resort en Utah. (donde los ninos le encanta pasar Spring break) en el poster habias unas palabras "Ve

grande o Ve a tu casa" no tenia idea de lo que eso significaba. Fue mi hijo el mas grande Brad quien me explico, me explico de la mejor manera de que los padres no supieramos de todas las cosas locas que los adolescentes hacen. Porque algunas de esas cosas, esas cosas como wake boarding y Flipping midar o esquinado y brincando en tubos de metales solo por diversion. Pero la parte que me da miedo es saber que mis hijos van cuesta abajo a como ellos pueden ir para cachar aire. (ahora ustedes saben porque yo prefiero quedarne abajo para tomar fotos)

La frase "Ve grande o Ve a tu casa" es un a promesa a la vida de empezar a vivirla llena. A como yo pensaba en la promesa y pense que la filosofia era la misma para los padres de Nathan.

Carmen menciono que el preferido juguete de Nathan era un muneco, un gorilla que podia cantar y brincar al rededor cuando empujabas abajo. La cancion que el cantaba era "Hooked on a feeling" su parte favorita era cuando el gorilla cantana y bailaba.

Nosotros te extranaremos Nathan. Gracias David y Carmen por compartir a su hijos con nosotros.

**Con todo nuestro amor,
La mama de David (Gina Johnson) y todos los padres de Sharing Down Syndrome Arizona.**



Algunos nos preguntas sobre pediatras para nuetros hijos, este es el doctor de leticia mi hija:

Dr Dwayne St. Jacques tiene la oficina en la 40 calle y la ray Rd.

4530 E. Ray Rd Ste 130 es en Ahwatukee para ser exacta.

Ramon y yo conocimos al Dr St Jacques cuando Leticia tenia 1 ano, despues que nuestra aseguranza nos mando una carta que este seria el pediatra asignado de nuestra hija. Nosotros no nos sentiamos muy bien en cambiarle de doctor a nuestra hija porque nos sentiamos bien con el doctor que ella tenia y quien diagnostico a Leticia.

Despues de que nos entrevistamos con el Dr. St. Jacques, nos sentimos mejor, sabiendo que fue una Buena eleccion. Solo a pasado un poco mas de 5 anos desde que Leticia empezo a ver al Dr. St. Jacques. El ha sido muy pasiente con todas nuestras preocupaciones acerca de Leticia y algunas veces falsas alarmas. Su personal trabaja rapido y presiso cuando yo hablo frustada por no poder dormir por la noche con Leticia enferma. La ultima cita con el fue cuando Leticia se levanto enferma y ese mismos dia la vio. Dr. St. Jacques ha vistos a otros ninos con discapacidades. Y siempre les hace exámenes regularmente. Pieso que el es estraordinario, sinceramente. Leticia se siente muy comfortable con el doctor y sus dulces enfermeras.

Tengo que decir que Lisa la enfermera es exelente si tengo alguna preocupacion por algun medicamento o no estoy segura de que tanto medicamento darle a Leticia, ella es genia respondiando a mis llamadas lo mas pronto posible .

Piendo de veradad que Saguario pediatic tiene el corazon para enfocarse en nuestros hijos. Nosotros somos unos pacientes muy feliz y queremos que el Dr St.Jasques sea el pediatra de nuestra Leticia por muchos anos.

La mama de Leticia,

Theresa



Queridas familias,

El verano esta aqui y nosotros esperamos por eso para las vacaciones de la escuela. Y eso significa que algunos de nuestros hijos iran a clases de verano este ano (ESY) es un programa de verano.

Nosotros tendremos algunas actividades este verano y te invito a ti y a tu familia a que vengas a disfrutar con nosotros!. En junio tendremos "TLNSE Trae un plato a compartir", el dia es sabado 19 de junio de 5:00 pm a 8:00 pm, trae tu siilas o cobijas para que disfrutes debajo de la sombra de los arboles. Trae un plato a compartir de vegetales o fruta. Te veremos en el parque mariposa que esta en la avenida 31, entre Glandale y Northern en Phoenix. Habla con Lucia Saenz si tienes alguna pregunta (602) 481-8363.

El dia Viernes 16 de Julio al dia 18 de Julio es un fin de semana, un grupo de familias estan planeando irse de campamento a Sedona. el costo sera de \$16.00 lo cual consisite en 8 personas y un carro. y si tu quisieras pagar por un espacio mas para otro carro pagarias la cantidad de \$5.00. El costo total por este fin de semana seria de \$32.00 y el costo de la comida es no mas de \$15.00 por persona. Ninos menores de 3 anos no pagaran. Padres pueden traer comida especial para sus hijos menores.

Nosotros estamos planeando tener y este es nuestro menu:
Viernes por la noche

Canitas, tortillas de maiz, chile rojo con cebolla y cilantro.
Arroz y frijoles.

Desayuno para sabado y Domingo:

Chorizo, huevos con papas burrito

Cereal con leche, jugo de naranja y café.

Cena para el sabado:

Carnitas, hot dog & pollo, frijoles rancheros

Sandia, salsa, tortillas y refrescos.

Otros productos que podrias pagar:

Hielo, productos de papel, galletas, bombones, condimentos para la comida, carbon.

Por favor manda tu money order o tu cheque a nombre de la Sra Lucia Saenz antes de el 16 de junio.

Sra Lucia Saenz

4849 89th Ave.

Phoenix, Az. 85037-1136

602-481-8363

Manda tus fotos!!!!

Sharing Down Syndrome tiene su pagina para poner fotos de tu familia, por favor manda tus fotos a la oficina y Romeo y Claudia Sanchez lo pondran en la pagina. Ellos

están dedicando su tiempo para esto y asegurarse que nuestros dulces niños estén en la página.

Si te gustaria escribir acerca de tu niño en TLNSE en la seccion de el periodico manda tu informacion con la foto de tu hijo, y te aseguramos regresarte la foto, manda esto a la oficina de sharing, con atencion a Thresa G. Cervantes.

Nuestra caminata!!!

Marca en tu calendario, nuestra caminata sera el 23 de octubre y queremos que cada una de las familias atiendan. Este día que celebramos a nuestros hijos, dejemos saber al mundo de que nosotros estamos muy orgullosos de ellos y que amamos a nuestros hijos de igual manera que a los otros niños.

Nosotros tendremos la caminata en Pera Club, es un lugar de SRP, la compania de electricidad.

Tendremos lo mas divertidos juegos y un brinca brinca y la comida sera gratis para toda la familias quienes se registren y nos acompañen!! Tambien tendremos quien hace la mejor salsa, inscribete y trae tu deliciosa salsa. El ganador se llevara a casa un gran regalo! Por favor habla a la oficina si tu quieres organizar este concurso de la salsa o participar.

"La cosa mas importante que un padre puede a ser por su hijos es querer a su madre."

-Theodoro Hesburgh

"Padres, así como madres, no nacen padres o madres, los hombres crecen para ser padres y el rol de padre es muy importante en su etapa."

-De David M. Gottesman

"Un papa es quien trae una foto en su cartera, donde supuestamente pone su dinero."

"Mi padre no me dijo como vivir; el vivio, y me dejo verlo a el hacerlo."

-Clarence B. Kelland 1881-1964

"Cuando yo era un niño de catorce años, mi padre era un ignorante, yo casi no podía estar alrededor de un Viejo hombre. Pero cuando llegue a los veintiuno, yo estaba muy ansioso de como ese Viejo hombre habia aprendido tanto en siete años."

-Mark Twain, 1895-1910

"Nosotros aqui de Sharing nos nos gustaria expresar nuestros amor y gratitud para todos nuestros querido padres quienes aman a sus hijos."

FELIZ DIA DE EL PADRE!!!!

We are always updating our records. Have a new phone number or address? New to Arizona? Complete the information on this form and send it to the address below, or email it to gina@sharingds.org.



Work Phone: () -

Child's Name: _____

Child's Date of Birth: _____

Your Name: _____

Employer(s) of Parents: _____

Address: _____

Family's Ethnic Origin(s): _____

City/State/Zip+4: _____

(This information is required for United Way and other supporters.)

Home Phone: () -

Sharing News is a free newsletter produced monthly by Sharing Down Syndrome Arizona! Inc.

Sharing Down Syndrome Arizona! Inc is a non-profit agency. We appreciate your support. Donations can be sent to:

Sharing Down Syndrome Arizona! Inc
745 N. Gilbert Rd. #124 PMB 273
Gilbert, AZ 85234
(480) 926-6500

You can also contribute through United Way by earmarking your donation with our address and phone number above. The United Way-Valley of the Sun ID number is 1175.

NONPROFIT ORG
AUTO
U.S. POSTAGE PAID
PHOENIX, AZ
PERMIT NO. 5300

Gina and Curt Johnson
Sharing Down Syndrome Arizona! Inc.
745 N. Gilbert Rd. #124 PMB #273
Gilbert, AZ 85234
Address Service Requested