

GREATER CLEAR LAKE Families Exploring Down Syndrome

Calendar of Events

Monthly Meetings:

6:30 pm Pizza & talk
7:00 pm Speaker
United Way-Bay Area
Bldg., 1300 Bay Area
Blvd., Conf. Room A.
Child care provided.

July

19 Creating a Portfolio
for Your Child

August

20 Job training and
Employment
Wendy Hodson-
Williams, BARC
Opportunity Center

Events:

September

11 2nd Wine Tasting
Fundraiser
7 to 9 pm
D'Vine Wine
~Kemah

November

8 2nd Annual
Conference
Education,
Medical/Therapy
and Adult topics
8 am to 4 pm
Life Tabernacle
Church

Contents

A Word from the Sec'y	2
Board & Committees	2
FEDS Golf Classic	3
New Members	4
Meet Our Member	4
Book Review	6
May Social	6
July Meeting	8
Conference	9
Wine Tasting Fundraiser	9
Volunteers Needed	9
Inspiration & Thanks	10

Inclusion: A Place or a Way of Life?

By Joanie Garro, MA, BCBA, CT, GCLFEDS Director



You might hear the term inclusion in a variety of ways depending on your occupation, your involvement in the community, or your child's ability level. You may use the term inclusion if you are a geologist. You may apply the process of inclusion if you are a paleontologist or you may advocate for inclusion if you are involved in special education in a public school setting. But what exactly does this term inclusion mean? Some basic definitions of inclusion are:

- a. the state of being included.
- b. a relation between two classes that exists when all members of the first are also members of the second
- c. the act or practice of including students with disabilities in regular school classes, (<http://www.merriam-webster.com/dictionary/inclusion>, 2008).

The latter definition will be the focus along with an extension of personal definitions and experiences. Inclusion can and should most definitely be a way of life in school, but it should also be a way of life at home, in the community, at church, and for any or all events in life.

In order to understand inclusion we must address the legal definition and how this term came about. Many parents and educators are surprised to learn that the word "inclusion" is not in

the statute (although "mainstreaming" is). According to the most recent Federal law, IDEA 2004, inclusion is addressed in the Least Restrictive Environment (L.R.E.) and mainstreaming. The statement for L.R.E. is:

(A) In general - To the maximum extent appropriate, children with disabilities... are educated with children who are not disabled, and... removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability of a child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily. (Individuals with Disabilities Education Act Amendments of 2004, P.L. 108-446, 20 U.S.C. § 1400 et seq.)

Mainstreaming is another legal term that means the practice of placing children with special needs in regular classrooms for at least a part of the children's educational program. Overall, IDEA can be summed up to say that children with a disability should receive a free appropriate public education (FAPE) in the least restrictive environment (LRE). The least restrictive environment (LRE) requirement is often referred to as inclusion or mainstreaming. (<http://www.wrightslaw.com>)

Continued on page 5



Collin, Anna & Mom Alicia
(GCLFEDS Secretary)

“With your help,
GCLFEDS is moving
forward!”

Please contact any
of us with
suggestions,
questions or offers to
help!

A Word from the Secretary by Alicia Dague

I am very proud to be a member of the GCLFEDS and honored to have been in on the “ground floor planning” for this awesome group! We are very fortunate to have a strong support group in this area. I leave each monthly meeting challenged with new things to try and contemplate.

There are so many great things in the works for families, educators and health care professionals in our area! One example is that our president, Anne Bernay, met this month with two of the nurses in the NICU at UTMB Galveston. As their information was very outdated, she talked with them at length about Down syndrome, about our group and the plans that we have to provide information to the medical community. From this meeting we have been invited back to give presentations to nursing staff, interns and residents of UTMB Galveston. Anne provided packets of information for the staff as well as new parents that will come through UTMB. If you have a contact in an area hospital, please let us know and we will be more than happy to meet with them!

In order to produce

programs such as these, we must have the finances to back the plans. That is why it is so important for us to make the most of each of our fundraisers. I do not see myself as a good fundraiser - like some of you, I feel somewhat uncomfortable asking for money even though I know what a worthy cause GCLFEDS is. Let me just tell you how easy it really is: it is as easy as sending out a letter or an email with your child’s picture at the top and telling a little bit about our group’s purpose/vision and something about your kiddo! It amazes me every time how quickly and easily people respond and how often companies are willing to give to such a great cause.

As secretary of GCLFEDS I am currently wearing several different hats, any of which I am most happy to share or pass on to another willing member. Public relations, recently taken over by Lilliana Monita, includes several different responsibilities. One of these is advertising our meetings and events in local papers. We currently advertise in Southbelt Leader, Clear Lake East Newsletter and the Neighborhoods section of the Houston Chronicle. If

you know of another paper that we could be advertising in, please provide us with the information. If you are interested in helping out in any way, Lillie would welcome any input and assistance.

Yet another area that I am involved in is the GCLFEDS Library. I am very happy to announce that we have added 25 new items: books, brochures and videos! Stop by <http://clearlaked.org/librari/y/> and check out what we have available. We are always looking to add new items so if there are resources that you no longer need, we will be happy to add them to our library. We are currently seeking a Librarian and if you are looking for an easy way to get involved this would be perfect for you as the work is minimal.

GCLFEDS is an amazing group to be a part of with great things to come that you will absolutely not want to miss out on! It is the desire of the Board to get as many people involved as possible; we don’t want anyone to feel like an outsider but to know that you are each an integral part of GCLFEDS success. With your help, GCLFEDS is moving forward!

Board of Directors & Committees

President	Anne Bernay	pres@clearlaked.org	832-457-2775
Vice President	Ellen Lachney	vp@clearlaked.org	281-935-7327
Secretary	Alicia Dague	sec@clearlaked.org	832-275-9365
Treasurer	Open	treas@clearlaked.org	
Director	Denise Chapman	director@clearlaked.org	281-283-3561
Director	Joanie Garro	education@clearlaked.org	832-483-1869
Committees			
Outreach	Beth Haas	outreach@clearlaked.org	832-689-5961
New Parent	Tiffany Perez	newparent@clearlaked.org	
Public Relations	Lilliana Monita	pr@clearlaked.org	
Webmaster	Joel Burdeaux	joelburdeaux@gmail.com	

Golf Classic a Wonderful Day for Golfers and FEDS

The 1st Annual FEDS Charity Golf Classic on May 9 at Timber Creek Golf Club in Friendswood provided a wonderful day of golf while raising funds to support GCLFEDS programs. It was a beautiful spring day; workers and golfers alike enjoyed the morning. Twelve teams teed off at 8 a.m. and competed in a scramble format. Many mulligans were purchased and used by the golfers to remedy slices and hooks! The Easy Eagle hole was

popular – every team paid for a “Tiger Woods” drive that had them lying 1 stroke at the 150 yard marker. Play was followed with a hamburger and chicken lunch and lots of laughs about the playing prowess of the teams during the day. Door prizes included clubmaking sessions courtesy of Golfsmith, a gift basket donated by Gringo’s, a Barnes & Noble gift certificate and more.

The team of Castillo,

Castillo and Romeo took top honors with the best gross team score of 56. Haas, Durkin and Elms posted a 33 to win the best team net prize. Both teams earned new golf bags.

Individual honors went to Nolan Strange for closest-to-the-pin and Dennis Engelbert for the longest drive. Both were awarded certificates for two rounds of golf courtesy of Timber Creek Golf Club.

The volunteers that were so kind to help on the day of the tournament are greatly appreciated. We couldn’t have done it without them! Thank you to Courtney Benninghoff, Anne Bernay, Alicia Dague, Joanie Garro, Ellen Lachney, Lillie Monita, Lori Robinson, Linda Rose, and Sharon Taylor. And special thanks to all of the FEDS members who solicited sponsors!

Join us for an even bigger and better event in 2009!



Durkin, Elms & Haas



Romeo, Castillo, & Castillo



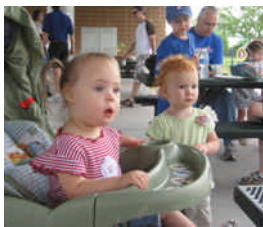
More pictures on www.clearlaked.org

Thank You to Our Generous Tournament & Prize Sponsors

- P Texas Children’s Hospital
- P Greenbriar Real Estate Services
- P Amegy Bank of Texas
- P Atkins, Inc.
- P Golfsmith
- P Kroger
- P Gringo’s
- P Barnes & Noble
- P Shipley’s Donuts – League City
- P Golf, Etc.
- P Father’s Joy
- P Eddie & Charlotte Sanchez
- P Kim & Mark Roffman
- P Linda Rose
- P Anonvmous Team Prize Donor

Thank You to Our Hole Sign Sponsors

- P Texas Wealth Management
- P Steve Rhatigan
- P Dr. Thompson Bogert, D.D.S.
- P Children’s Ear, Nose & Throat/Dr. Joseph Edmonds
- P Pediatrics Plus
- P Bay Glen Animal Hospital
- P Pennington-Chen Real Estate/Virginia Metcalfe
- P Remax/Faron Daigle
- P San Jacinto Methodist Hospital-Baytown
- P Trammel Crowe Residential
- P Dentistry 4 Children
- P Georgetown Stamps
- P Tubular Resources
- P Lone Star Sportswear
- P House and Lawn.com
- P Charlcya Wheeler § Collins Family
- P Reat Family § Bernay Family



Macie & Mattie



Sarah (middle) & friends Clare & Peter



Solana, 5 months

Welcome New Members!

Thank you for supporting GCLFEDS.

Blanka & Michael Brhlik and Sarah, age 8

Sasha & Andrew Camacho and Solana, age 5 mos.

Congratulations to the Trahan Family on the arrival of daughter Addison Yvette on May 24!

Become a member today!

Register online at <http://clearlakeds.org/membership-application/> or mail the form available on the website.

Membership has its privileges! Some new things that have been added recently to the "Members Only" area are videos of past meetings, a photo gallery where you can upload pictures and a bulletin board where you can ask other members questions about issues that you are having.

Meet Our Member: Sarah Brhlik

Just Challenge Me !!!

Our daughter Sarah was born on a beautiful September day at the University of Michigan Hospital. Our midwife started to suspect that something wasn't quite right shortly after her delivery and soon a string of experts started to visit our suite. It became quite obvious that they all agreed that the baby might have Down syndrome. And so she did. Thankfully, contrary to the book about infants with Down Syndrome (which the hospital immediately supplied) Sarah did not have any immediate medical issues which so often affect our children. In the years that followed we came to appreciate immensely the fact that she remained healthy.

Like many parents in our situation, we experienced the feelings of uncertainty about what will happen tomorrow, next year, in twenty years. Sarah did

not care and just enjoyed her life. It was clear from the first few months that she is a born optimist. She explored the world around her with keen interest and enthusiasm using every capacity she could muster. We will be forever grateful for the support of all the wonderful therapists, teachers, and friends who helped her to stay on the right track.

Recently, I sat down and went through the notes my midwife encouraged me to write down shortly after she was born. I was surprised how completely ignorant I was about Down syndrome in the first place and how this lack of knowledge influenced my perspective. I, eventually, learned a lot of facts about Down syndrome. However, Sarah taught me and the rest of the world that she will be herself and didn't care much what the "smart books" say. She has plenty to say about who



Sarah and brother David enjoy a recent ski trip.

she is and who she will be herself.

It is hard for me to believe she will be nine in September. She has become such a big girl. She is so proud of herself being a second grader, and being able to go to school to be with "her" kids. She is thrilled to be able to read books to us and the signs around our neighborhood. She is a great helper at home, especially with cooking. She is an accomplished swimmer, skier, skater and gymnast. She is going for her first triathlon this fall. She is dreaming of becoming a

ballerina or a princess some day. And she cracks us up all the time.

Sarah enjoys being with other people, but she especially worships her brother, five years older than she, and her dad. They both have been instrumental in her life and her accomplishments. Neither of them ever gave much thought to her limitations, just the opposite - they challenged her and she responded. She truly has become one sizzling kid....and we can't wait for more from her.

- Sarah's mom, Blanka

Inclusion, cont.

Continued from pg. 1

Although the concept of inclusion began as a way to ensure that children with disabilities were educated at the same school they would have attended if they did not have a disability, inclusion today is considered an all-encompassing practice of ensuring that people of differing abilities belong, are engaged, and are connected to the goals and objectives of the whole wider society at school, home, and in the community. What does this look like in the school or community settings?

School: In the past 20+ years of teaching, I have seen an inclusive attitude evolve from just an idea, time, or place to a true way of life. In the school setting inclusion practices can take on many different forms with no limits or boundaries. Children with disabilities can and should be included in all aspects of school such as field trips, class yearbook pictures, homeroom activities, assemblies,

after-school activities, academic classes, and graduation.

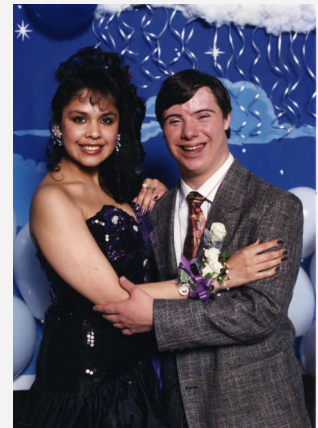
One parent I interviewed described his experience with the "inclusion" of his daughter with her peers in school for more than 10 years. He said, "Inclusion is making kids part of the curriculum that all the other kids experience together." The experience his daughter had was very positive. He felt by including his daughter with her peers, she wasn't "boxed" in someplace where someone else thought she should be. It brought out her true intelligence, promoted her interaction with all types of kids, and helped her relate to everyone. He went along to say that there are great benefits to the students in the general education settings too. They benefit by learning that all kids learn differently but deserve the same rights and treatments as they do. Inclusion builds character and fosters interdependence and

independence. And finally, "school is not just about grades and passing, it's about relationships."

Inclusive settings do help promote true friendships between children with and without disabilities as I was able to experience first hand. One day a substitute paraprofessional walked into my classroom (a self-contained class) with a look of amazement, joy, and excitement. She was a mom in her 40's who was just beginning to substitute in special education. I always ask people their background experience in order to assess training needs. She proceeded to tell me about her best friend in Maryland. She said that she met her friend when she was a young girl and they had remained friends since then. Her friend inspired her to look beyond the perceptions society has about people with special needs and to embrace differences. Because of her best

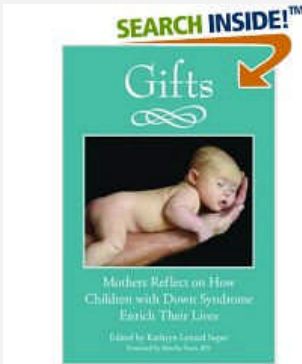
Continued on pg. 7

"School is not just about grades and passing, it's about relationships."



Joey Garro and his prom date. They became friends in high school because Joey was included in her regular ed. journalism class.

Book Review by Elizabeth Stevens



Gifts – Mothers Reflect on How Children with Down Syndrome Enrich Their Lives
 By Kathryn Lynard Soper and Martha Sears
 (2007, \$12.89 on Amazon.com)

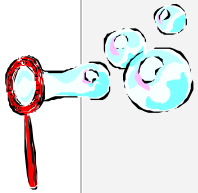
For me, as a new parent of a child with Down syndrome, the book Gifts – Mothers Reflect on How Children with Down Syndrome Enrich Their Lives was a lifesaver. Unlike some of the other books that are given to new parents and contain practical information about health and therapy issues, Gifts provides emotional insight. The book is a

collection of essays from sixty-four mothers of children with Down syndrome. The essays are very personal and honest stories from mothers who have experienced both the heartbreak of learning that their baby has Down syndrome and the joy that inevitably follows when they get to know their baby.

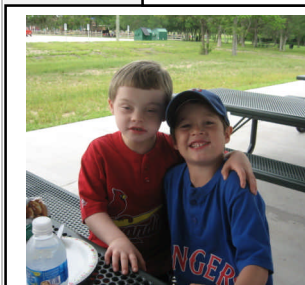
The editor of the book, Kathryn Lynard Soper, is an author and mother of seven children, including her youngest, Thomas, who has Down syndrome. She explains in the introduction that the title Gifts “captures the refrain commonly heard from

parents of children with Down syndrome—the lives of their children are cause for celebration.” The theme that comes through from reading the essays is that the shock and emotional turmoil that comes with learning that your child has Down syndrome is almost universal, but so is the love and happiness that your child will bring to you -- and the happiness lasts a lot longer.

May Social Brings Families Together



Challenger Park was the site of the GCLFEDS May Social on Saturday, May 17. Families came out in droves to enjoy the fresh air, food, and chance to meet other members. The kids enjoyed chasing each other around, playing in the bubbles from the bubble machine, making visors and streamer wands. The nearby playground also saw lots of use. Moms, dads, grandparents and friends had a chance to exchange stories and share the joys of raising our kids with and without DS. Several new babies were in much demand for cuddles and hugs.



Above left: Chris & Anna Dague
 Above right: Blanka Brhlik holding Ella Haas, Joanie Garro
 Left: Buddies Peter Bernay & Collin Dague
 Right: Chowing Down!
 Below Left: Kids making visors and wands
 Below right: Crystal Cortez chasing Annalee Haas



A special thanks to Tiffany Novick for planning and organizing the event, Elizabeth Stevens for helping with the food, and Beth Haas for reserving the pavilion for us.

Inclusion, cont.

Cont. from p. 5

friend, she wanted to work with people with special needs to help promote friendships with peers. The substitute was so excited when she learned she would be going into the general education settings with children with disabilities. She knew that she was in the right place. Her best friend in Maryland, now an adult, has Down syndrome. Their true friendship started at a young age with no boundaries, just an inclusive attitude. The substitute concluded that she doesn't pity her friend or feel like she is the only giver in the friendship. She said that her best friend helps her in so many ways by giving her advice and keeping her humble.

In a school setting people may define "inclusion" in different ways by setting time limits to it or by assigning a label to an "inclusion class", but inclusion should really be a way of thinking creatively of how the school can accommodate and modify the existing

setting to meet the individual needs of all children at all times. It should be a philosophy taught to children at a very young age. So if you experience times in a school setting where you feel an inclusive environment is not yet set up, don't fret. This can just be an opportunity to pave new roads. There are no rules about places or times for inclusion to exist in schools. Be creative. Think of all the possibilities for your child and those of others. No limits, no boundaries, no rules, no secret formula for times. You can even say, "So this inclusion opportunity doesn't exist yet? Well then let's work as a team to start something new because this will benefit all involved!"

Community: In the community, the concept of inclusion is slowly becoming a way of life. Some may say that their community or place is inclusive because they have wheelchair ramps or accessible bathrooms, but inclusion in the community goes beyond any

physical modifications. We see children with special needs belonging to dance or sports teams alongside their peers. We experience the young adults at various establishments working regular jobs alongside their peers. Some community colleges offer classes for individuals with mental retardation after they leave the public school setting. We even see couples with special needs such as Down syndrome getting married and going through everyday struggles and joys. One of my personal joys of inclusion in the community has been working with local churches to ensure that families with children with disabilities are included in all church functions. This has been successful by not building classrooms for children with special needs, but by changing attitudes. Although I still hear families say, "I didn't think my child could attend Sunday school, "I hope

Continued on pg. 8

Websites to Try

www.wrightslaw.com/info/lre.index.htm

www.inclusion.com

www.uni.edu/coe/inclusion/

www.circleofinclusion.org

www.kidstogether.org/inclusion.htm

www.specialednet.com/inclusion.htm

"Advocating for an inclusive environment is far from over..."



Inclusion, cont.

Continued from pg. 7

church becomes a safe place for ALL families to grow and experience community.

Our goal in the community should be that families will think and say, "Yes! My child could be part of that team," or "My child can go to the local library story time," or "My child can apply for a scholarship for college."

Advocating for an inclusive environment is far from over; we still experience physical and emotional barriers. However, if each of us change our way of thinking about it and start talking to others in

our community, our family, and school personnel, we can all make a difference. Inclusion as a way of life will require each of us to re-define our expectations for children of all ability levels.

In the ideal world that I envision, playgrounds in every community have access for wheelchairs and walkers to get up on play equipment so children can go down slides. We would find young children adapting their toys so that their 'friends' with physical limitations can play with them. We would hear waiters asking children (not the parent) what they want to order and watch as the

child presses a voice output device to order his/her own food. We would reach into every 5 year old's backpack and see the homework for sign language that is part of the curriculum. There would be no physical or emotional barriers for anyone.

So how will you define inclusion in your school, your home and your community? You see, how we characterize inclusion can be very personal based on our past and present experiences. What vision do you have for an inclusive world?

Thursday, July 17
United Way Service
Center-Bay Area
1300 Bay Area Blvd.

A portfolio is a terrific tool for communicating to teachers, therapists and schools important information about your child. There are many different forms and the content can vary

depending on the child and the purpose. Come learn how a portfolio can help your child, what to include and how to produce it and use it. We'll have plenty of examples to give you ideas!

6:30 pm
Pizza and informal
parent discussion

7:00 pm
Speaker

Child care provided.

July Meeting – Creating a Portfolio

GCLFEDS 2nd Annual Conference

Saturday, November 8, 2008

8:00 am-4:00 pm
Life Tabernacle Church
9901 Windmill Lakes Road
Houston, TX 77075

Speakers on 3 Topic Areas:

- Education
- Medical/Therapy
- Adult Topics

Child care and lunch available



Keynote Speaker: Karen Gaffney, self-advocate who swam the English Channel and Lake Tahoe

Call (281) 935-7327 or email vp@clearlakeds.org for more information

2nd Annual Wine Tasting Fundraiser D'Vine Wine ~ Kemah

Thursday, September 11 \$25 per person
7-9 p.m. \$40 per couple

Enjoy:

- | | |
|------------------|-----------------------|
| § Wine tasting | § Live music |
| § H'or douevres | § Massages |
| § Silent auction | § Good conversation |
| § Door prizes | § Supporting GCLFEDS! |

Tickets available now – Call 832-457-2775 or go to
www.clearlakeds.org for more information

Volunteers Needed!

Help GCLFEDS with the following activities:

- Librarian: Maintain and add to the library and fill member requests for books at meetings or by mail
- Community Outreach Committee: assist in contacting medical professionals, hospitals, and others in the community; help distribute materials and present to these groups to promote inclusion and acceptance
- Wine Tasting Committee: Help organize our Sept. fundraiser; solicit items for silent auction; sell tickets; make centerpieces & more
- Conference Committee: help organize the Nov. conference by assisting with PR, booth sales, registration, donations, childcare & more

Contact
gclfeds@clearlakeds.org
or call 832-457-2775 to volunteer.

A Little Inspiration



Down Syndrome
Dolls: Downi
Creatons, Inc.

[www.downicreatio
ns.com](http://www.downicreatio
ns.com)

This 501(c) (3) non-
profit makes
collectible-quality
dolls with the 13
distinctive features
of Down syndrome.

Their mission is to
bring comfort and
joy to those with
Down syndrome
and to educate the
general public
about the disorder.
The dolls retail for
\$174.95 including
shipping and
handling. There are
eight different dolls.

National Down
Syndrome Society:
Free Documents for
Download

www1.ndss.org

See Information
Topics, then
Publications to view
free downloadable
publications on
everything from
speech to sexuality.

Thank You to Our Sponsors & Volunteers

Our gratitude and thanks to the following
generous donors:

Texas Children's Hospital

Our volunteers make all of our programs
possible. Special thanks to:

- Tiffany Novick – organizing a fabulous Spring social
- Tracie Fredericks – giving an informative presentation on Potty Training at our June meeting

- Tiffany Novick & C.J. Ruiz – providing delicious desserts for our June meeting
- Denise Chapman – making the summer early intervention program a reality!
- Anne Bernay – developing the scholarship program and speaking to UTMB-Galveston nurses
- Joanie Garro, Blanka Brhlik, Elizabeth Stevens – writing for our newsletter this month
- Jennifer Smith-Anderson – providing contacts for our outreach to hospitals

Greater Clear Lake
Families Exploring Down
Syndrome

Phone
(832) 457-2775

E-mail
gclfeds@clearlakeds.org

Website
www.clearlakeds.org



About Our Organization

GCLFEDS provides support
and resources to
individuals with Down
syndrome and their
families. Our family support
programs educate and
empower families to
ensure the success of their
children in the larger
community. Monthly
meetings, socials, new
parent support, a lending
library and annual
conference are a few of

our activities.

GCLFEDS promotes
awareness, understanding
and inclusion in our
communities. Through
presentations and the
DVD entitled "Living with
Down Syndrome: Turning
Fear Into Hope" we help
medical professionals and
hospitals provide a more
positive outlook to new
parents. We are working

with local school districts
and colleges to ensure
the best education for
our children.

GCLFEDS focuses on
ensuring a positive
community outlook and
ample opportunity for
individuals with DS to
succeed. We believe in
our kids and know that
they can do great things!
Won't you join us?

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