Salinas Circle for Children

May 2011 Newsletter

** Living with Spina Bifida **

Andrea is 12 years old and in the 6th grade. She likes to go swimming, play with her dog, and have friends over. She's been in three dance recitals, and she even received a standing ovation once. She's traveled to Canada and many places in the United States, and next summer she hopes to go to Scotland. When she's older, Andrea wants to be a chef.

Like you, Andrea is interested in many things and can do a lot of stuff. What might be different from you, though, is the fact that Andrea can't walk. Andrea has spina bifida and uses a wheelchair to get around.

What Is Spina Bifida?
Someone born with spina bifida has an opening in the spine. A healthy spine is closed to protect the spinal cord, a bundle of nerves that sends messages back and forth between your brain and the rest of your body. The messages tell your muscles to move so you can kick a soccer ball or pick up a pencil. The messages also tell you about sensations on your skin, so you know to pull your hand away from a hot pot.

When a baby is growing inside its mother, the spine and spinal cord are developing. But sometimes part of the spinal cord and spine don't grow the way they should, leaving an opening where the spinal cord may protrude outside the body. When this happens, a baby is born with spina bifida, a term that means "split or open spine."

Because of the opening in the spine, the nerves of the spinal cord may be damaged. A spinal cord that's damaged may not be able to do the important job of getting messages to and from the brain. Usually when your brain says "kick the ball," the nerves of your spinal cord carry that message that tells your leg to kick.

These messages may not be able to get through if a person has spina bifida. The person may not be able to move their muscles the way other people do. This is called paralysis, which means a person can't move some muscles or to feel things on some parts of the body.

What Are the Different Types of Spina Bifida?
One kind of spina bifida can go unnoticed. With **spina bifida occulta**, the opening in the person's back is covered by muscle and skin and the spinal cord is usually normal. There may be some problems with the spine, or there may be no problems at all.

Another type of spina bifida is called meningocele. This involves the meninges, the membranes that cover the brain and spinal cord. Meningocele is the name used when just the meninges - no nerves - push through the opening in the vertebrae. The meninges form a fluid-filled sac that is usually covered with skin. The spinal cord is normal and a person with a meningocele usually has no problems. A person with meningocele will need surgery to prevent any nerve damage later.

When most people talk about spina bifida, though, they mean **myelomeningocele**, from words meaning "spine" and "swelling." In this type, the baby is born with a sac protruding from the opening in the spine. This sac contains nerves and part of the spinal cord. About one in 1,000 babies born in the United States have this type of spina bifida.

Because the spinal cord hasn't developed normally and some nerves may have been damaged, a person with myelomeningocele will have some **paralysis.** The amount of paralysis will vary, depending on where the opening is on the back. The lower down the back the opening is, the fewer nerves are affected and the less paralysis there is. This is why some kids with spina bifida can walk and some can't. To help them get around, kids might use crutches, leg braces, or wheelchairs.

Andrea, our dancer, was born with an opening in her lower back, just below her waist. She can move her legs but not her feet and ankles. Her skin has feeling only down to her knees. When Andrea was younger she walked with braces and crutches, but now she uses a wheelchair.

Like many other kids with myelomeningocele, Andrea also has **hydrocephalus**. This happens when there's too much fluid in the brain. Some people with spina bifida may have learning problems, but most have normal intelligence. Most kids with spina bifida have some problems with their bowels and bladder. The nerves that send and receive messages from the brain can't do their job, so it's hard for kids to know when they need to go to the bathroom.

Why Do Kids Have Spina Bifida?
No one is really sure why some kids are born with spina bifida, doctors and scientists have found some possible reasons. They've learned that **folic acid** is very important, especially when a baby is growing inside its mother. Folic acid is one of the B vitamins found in foods like broccoli, spinach, egg yolks, and oranges. If a woman doesn't have enough folic acid in her diet while she's pregnant, she may be more likely to have a baby with spina bifida. Luckily, special vitamins containing folic acid are available for pregnant women.

A woman who has a high fever early in her pregnancy also may be at higher risk of having a baby who has spina bifida. Scientists are also studying the roles that genes, certain chemicals, and medicines might play in causing spina bifida.

What Do Doctors Do?
From the moment Andrea was born, doctors have been an important part of her life. When she was just a few hours old, she had her first surgery. Doctors gently pushed her spinal cord back inside her body through the opening on her back, and then closed the opening.

When she was 2 days old, the doctors put in a shunt, a device that drains the extra fluid in the brain. Since then, Andrea has had several operations, mostly to replace her shunt. In addition to surgery to keep her shunt working, a kid with spina bifida might need surgery on the feet, hips, or spine.

Kids like Andrea also need checkups a couple of times a year and may see a team of medical people. This team may include pediatricians, orthopedists, surgeons, physical therapists, and occupational therapists. They want to help the person to be healthy and as independent as possible.

What Is Life Like for Kids With Spina Bifida?
Living with spina bifida isn't exactly the same for each kid who has it. But for most kids, it means taking extra care of their bodies and paying attention if something seems wrong. It can mean taking longer to do things, because braces, crutches, and wheelchairs just aren't as fast as walking and running. But as Andrea has shown, that doesn't mean she can't do exactly what she wants to do!

Reprinted from www.kidshealth.org

*****President's Message*****

I hope everyone enjoyed a nice relaxing Easter with lots of ham and marshmallow peeps. It's amazing that we are already in the month of April and heading straight towards May. How time flies when we're busy. And Salinas Circle for Children members are busy indeed. We just finished off our 10 in 10 campaign, which was recruiting 10 members in 10 weeks into our organization. Although we did not get 10 new members, we are on our way. Elaine Hunt, our membership chair, organized a wonderful gathering at Portobello's on Friday April 8th and it was fabulous. We had many guest and lots of fun. Thank you to Portobello's and Gifts on the Go for your support!! And we did get 5 new members and more to come. Because of this great outcome, we are extending our 10 in 10 campaign. Let's see if we can get the rest!! I know we can.

Looking into the future, Salinas Circle along with other special needs organizations in Monterey County will be at Del Monte Center on Saturday May 7th for Celebrate Mama. It's a great event for moms, so come out and enjoy the day. Salinas Circle is also a sponsor for a fundraising effort for Tatum Bakker on May 14th at Angelina's Pizzeria. Project Playroom has been organizing this event for a fun family pizza and game day to help a wonderful family and their beautiful baby. Please read the insert about the Bakker family in this newsletter and spread the word.

We are also looking forward to June for a Past and Present Member Luncheon for Salinas Circle. It's such a great time to catch up and find out what we are doing in our 45th year of giving. Thank you to past member, Simi and current and longtime members, Carolyn and Vickie for helping pull this event together. Please keep your eyes open for an invitation in the mail. I am really excited to meet past members that have had such a strong impact on Salinas Circle in past years!!

I have always used this saying, "Nothing great was ever achieved without enthusiasm." I am not sure when or where I found this, but it popped up the other day and FINALLY I feel that I'm using this phrase in my daily life. I balance two lives, being a teacher to a great group of kindergarteners and I help run an organization with a great group of women. I feel that without enthusiasm neither of these, my classroom or Salinas Circle, can be successful. And I realize that I only have two things to balance in my life when many members balance 2, 3, 4 and maybe 5 things in their life. It takes great dedication to volunteer and be active in the community. Each of our members show great enthusiasm for just being a part of this organization, coming to meetings, helping to organize so many events during the year and bringing thought and care into Salinas Circle. I want to thank you all for anyone who is a part of this organization and does things extra for the community. I don't think I can ever say thank you enough. ☺

Smiles, **Kelli**

*****Meeting Notice*****

TUESDAY, MAY 3RD

6:00pm for social/food & 6:30 for meeting

Kathy Hemenway's house: 22317 Berry Drive, Salinas

Directions to meeting place:

From Highway 68, take the River Road exit

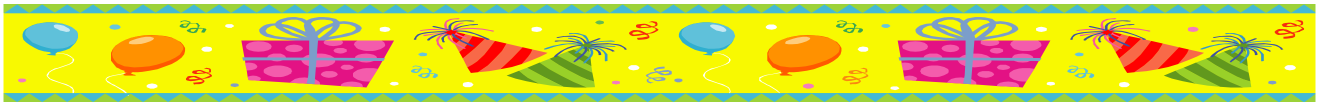
Drive 3 ½ miles South on River Road, right turn onto Berry Drive (next right after Indian Springs Road)

Drive 1 mile up Berry Drive and you will see a covered group of mailboxes on right side, on the left side is a post that reads "22317"

Take the concrete driveway (all the others are asphalt) up the hill

22317 Berry Drive is a 2-story tan house with tile roof

Remember your secret pal for April. Active members, if you cannot attend the meeting, please notify Teresa 809-4413 or Kelli 206-1883.



*****Happy Birthday*****

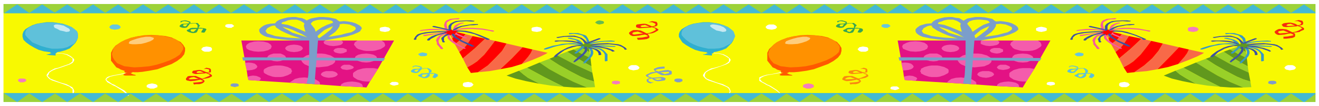
MAY

Jillian Jefferson

M. J. Viglizzo

Katelyn Jefferson

Sherrie Isaac



****Special Activity****

Carnival O' Pizza

a benefit for
Tatum Bakker

Saturday, May 14th
11:00am - 2:00pm

Angelina's Pizzeria
22736 Portola Drive
Salinas

All You Can Eat
Pizza & Soft Drinks

Adults: $10.00
Children: $5.00

Cake Walk
Milk Bottle Knockdown
Ring Toss
and more...

iPad Drawing
Silent Auction
Carnival Games

For More Information
Contact Project Playroom at
831-229-2433

Sponsored by:

project playroom

Angelina's pizzeria

Salinas Circle
for Children

Cypress MOPS

Tatum's Story, as told by Amanda:
This journey began for us as we walked into the hospital at 6am on Tuesday, September 28th, anxious for the birth of our third child, Tatum Elizabeth. I had a very routine pregnancy with Tatum, and though we had just bought a home and moved only 4 days ago, we were able to set the stress aside and look forward to a few quiet days with her in the hospital after my scheduled c-section.

Shortly into the delivery, our world was shattered...we were completely shocked to learn Tatum was born with Spina Bifida, and a tiny membrane was all that protected her exposed spinal cord at the hole at the base of her spine. As a related issue, she was suffering from Hydrocephalus--a very enlarged skull which often accompanies spina bifida--and the fluid had nowhere to drain. Due to the incomplete formation of her spinal cord, and nerve damage that has occurred, she does not appear to have control from the waist down.

Needless to say, we were shocked, confused, fearful...not knowing what the next moments, hours, days, weeks would hold. Everything we had taken for granted, with her two older siblings Olivia (5) and Wyatt (2) being born perfectly healthy, was suddenly replaced by the harsh reality that life as we knew it would never be the same...and we had many more questions than answers.

Tatum was flown that afternoon to UCSF's Children's Hospital, where she could get some of the country's most expert care for spina bifida. As we faced the realization that she would be whisked away, we gathered all the family who was there, and shared a beautiful moment...we laid hands on our precious angel and sent her off with prayers and blessings...placing our heartaches and hopes for sweet Tatum in our Savior's hands.

Two days later, Tatum had major brain surgery to place a permanent drainage shunt in her skull, and relieve the pressure on her brain, and also to delicately knit her spinal cord and surrounding tissues back together. She recovered and healed beautifully...until, unfortunately, a month later, she developed an infection in the shunt site and had to have it removed, treated, and a new one was placed a week later. We never could have imagined 3 brain surgeries for our daughter within the first 5 weeks of her life! And yet, now we have had a wonderful stretch of health and healing for Tatum, who is smiling, giggling and can feel all but her feet. She is a chubby, happy baby who truly brings joy and peace to all who know her.

We are so blessed to continue her follow-up care monthly with spina bifida experts at UCSF, and are becoming more familiar with the daily routines that make Tatum's life easier--around the clock catheterization, therapy 3x/week, and wearing a harness to help correct her hip dysplasia/dislocation. Our current hope and prayer is that we can avoid another surgery this year, which could be needed to place her hips, if the harness can't correct the dysplasia. We know we are at the very beginning of a lifelong journey with Tatum's care...but as we walk this path, we know in each mountaintop victory and valley of discouragement, we are not alone...God is guiding us and offering the peace and comfort to take the next right step.

To read more of this inspirational story, please visit:
http://www.caringbridge.org/visit/tatumbakker

Salinas Circle for Children
Membership Application

_____ **Active**, $30.00 per calendar year
I am interested in Active Membership and plan to attend meetings and will participate in planning and implementing fundraising activities.

_____ **Associate**, $40.00 per calendar year
I was an Active Member for a minimum of 5 years and will continue to assist with fundraising activities.

_____ **Sustaining**, $50.00 per calendar year
I am interested in supporting Salinas Circle for Children financially without obligation to participate in any activities.

Member Name: ____

Mailing Address: ____

City, State & Zip: ____

Home #:______________Cell #:______________Work#:______________

Email: ____

Birth - Month & Day: __________________________

Member Since: _______________ (if you know the year)

Please indicate how you would like to receive information regarding meetings, etc.

Email: ________ Phone:home_____cell_____work_____ US Mail: ________

Please mail completed form along with payment to:

Membership Chair
Salinas Circle for Children
P. O. Box 2064
Salinas, CA 93902

****Hostesses for 2011 Meetings****

May:	Alethea & Paula	Kathy Hemenway's home
June/July:	Summer Social	Teresa Slaton's home
August:	Pre-event, details to follow	Kathy Hemenway's home
September:	volunteers needed	Elaine Hunt's home
October:	Trish & Vickie	Alethea Leandro-Farr's home
November:	Carolyn & Elaine	TBD
December:	Holiday Party/Installation of Officers, suggestions welcome	

May 2011

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Salinas, CA 93902

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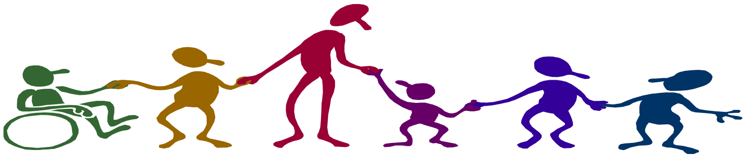
E-mail: salinascircle@aol.com
Web site: www.salinascircle.org

Salinas Circle for Children

The purpose of the Salinas Circle for Children is to raise and provide funds, and to perform needed services, to assist children with physical, developmental, and emotional needs in Monterey County.

Our mission is to provide the tools and support needed so they may thrive in their living and learning environments.



2011 BOARD OF DIRECTORS

President:	Kelli Hemenway
1st V.P:	Alethea Leandro-Farr
2nd V.P:	Paula Taylor
Secretary:	Terri Jefferson
Treasurer:	Tamara Schwartz
Annual Event:	Paula Taylor/Alethea Leandro-Farr
Membership:	Elaine Hunt
Sunshine:	Michele Maconachy
Communications:	Teresa Slaton
Hospitality:	M.J. Viglizzo
Special Activities:	Ginny Lott & Carolyn Sanders
Parliamentarian:	M.J. Viglizzo
Discretionary:	Alethea Leandro-Farr

Salinas Circle for Children is looking for fun-loving, hard-working volunteers to help us in fulfilling our mission.

Please come and see how you can assist us in helping the children with special needs of Monterey County.

If not you.....then who?