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Coming Events:

April 9th

March of Dimes Walk

April 16th

ECMO Conference

May 3rd

CCANN Luau

July 8th

Breakfast Conference

November 12th

**Neonatal Medley
Conference**

December 6th

**Eighth annual Holiday
Gala**

CCANN Introduces Our Poster Child: "Evie's Story"



Osteogenesis Imperfecta: A Quick Overview

By Emily Goines, RN (Evie's Mom)

Osteogenesis Imperfecta is a rare genetic condition characterized by a person having very brittle, fragile bones. There are currently an estimated 25,000 to 50,000 people in the United States living with this disease. OI is a lifelong condition with no known cure. It affects males and females equally. People are commonly classified into 4 types, Types I-IV. There are, however, more than 15 types that have been identified. And each person with the disorder can vary greatly in severity within each type. Some common characteristics seen include: blue sclerae, bone deformity, bone pain, short stature, spine curvature, loose joints, skin hyperlaxity, large fontanel, hearing loss by mid 20's, brittle teeth, vision problems, respiratory complications, fatigue, and larger than average head circumference. Most cases are caused by either a decrease in production of collagen (a major protein found in bone) or production of a faulty type of collagen. The condition is either

(cont'd from page 1) inherited when both parents are carriers or it can be caused by a random genetic mutation. A person with OI has a 50% chance of passing the condition on to their children. An affected child will have the same type of OI, but can vary in severity. In the more severe types, the disease is diagnosed via ultrasound around 22-24 weeks. Bowing of the long bones, fractures, bone shortening, and other bone abnormalities can be seen on ultrasound. Unfortunately it is near impossible to determine the type of OI based on ultrasound, so many parents are told to prepare for the worst. Babies with the most severe type, Type II, do not survive past the newborn period.

There is no known cure for Osteogenesis Imperfecta. There are a variety of treatments being practiced that can help manage chronic pain and help decrease the frequency of fractures. For example, a common treatment is getting an infusion of a medication called Pamidronate. Commonly called Pam, this medication is a bisphosphonate. It is given to increase bone density by inhibiting osteoclast production. This will delay the breakdown of bone and prevent the osteoblasts from building up bad bone. Another common treatment is intramedullary rodding. An orthopedic surgeon will place telescopic rods in the long bones (commonly the tibias, femurs, and humeri). These metal rods can grow with the patient, and they act to help brace and support the bone. The problem with most people with OI is that they lack the ability to support their own body weight due to having curvy and deformed bones. By placing rods in these bones, the bone is able to bear weight. This surgery has been instrumental in helping people with OI gain mobility and more independence. Physical therapy is also paramount in people with OI. Each time they fracture and need a cast, they lose muscle tone and strength. Without this, they are more likely to fracture again in the same place. It has been noted that hydrotherapy is an excellent way for a patient to gain strength with very little resistance.

It is crucial for a person with OI to have a multidisciplinary team of providers willing to collaborate and work together to help manage their specific symptoms. This can include orthopedic surgeons, pediatricians, geneticists, endocrinologists, dieticians, physical therapists, neurologists, and pulmonologists. Unfortunately, these patients are constantly in the hospital or clinics seeing different physicians and requiring treatments to meet their complex needs.



My daughter Evie was born with OI. It was the result of a random genetic mutation of the COL1A gene. Unfortunately, the specific mutation that occurred has never been seen before, and as far as we know there is no one else in the world with it. She is literally one-of-a-kind. We have no clue as to what her future holds. We do know that she falls somewhere between types III and IV. So, she is somewhere on the moderate to severe spectrum. She has proven to be very fragile. She has had over 12 fractures in her life thus far, most occurring from basic handling. We carry her on an egg crate mattress to offer her more stability. Evie is able to do tummy time on an exercise ball to help her develop and strengthen her neck and back muscles. We hope that one day soon she will be able to do tummy time on the floor and to eventually sit up on her own. Evie started getting Pamidronate infusions at 16 weeks of age due to her severity and frequency of fractures. We have already noticed a huge difference, not only in her strength, but in her length as well. She grew 0.5 inches a week after her first infusion. She will continue to get infusions of Pamidronate every 8 weeks for the foreseeable future. Life is going to be different for Evie. I never thought in a million years that I would ever have a child with special needs. It has helped me to grow in so many ways. And even though it is hard at times, one look at her and I know that it is all worth it. She is absolutely beautiful. She is strong, brave, courageous, and happy. I refuse to allow this disease to define her. She is perfect to me in every way.



I have worked for the past seven years as a Neonatal Intensive care nurse. It never occurred to me that my child would ever need the services I so frequently render to children from all over the Central Valley. In September of 2015 I gave birth to a beautiful baby girl named Evie. She was born with a rare genetic condition called Osteogenesis Imperfecta, or more commonly known as brittle bone disease. Evie has suffered from multiple fractures since birth, many occurring just from basic handling. She is extremely fragile, and will fight this disease for the rest of her life. Unfortunately, there is a lack of knowledge about this condition that makes it difficult to find adequate treatment for Evie. With the help and support of CCANN, it is my hope that we can educate healthcare professionals not only about this disease, but all conditions affecting neonates.



Together we can make a difference.





Advocacy March of Dimes—Walk for Babies

Team Neo Nurses and Friends (CCANN) will be kicking off 2016 March of Dimes activities this year. March for Babies-March of Dimes will be held at Woodward Park on April 9, 2016. Our team goal is to contribute \$6000 to the March of Dimes Foundation. There are many fundraising events planned this year to help fund March of Dimes Foundation research in saving our little premies.

T-Shirt Sales:

We have choices of v-neck and crew neck screen printing T-shirts for sale. The v-neck has been the most popular choice for the neo nurses. The cost of v-neck is \$20 each and \$8 will go to March of Dimes. The cost of crew neck is \$15 and \$6 proceed will go to March of Dimes. Any 2XL shirts and above will cost \$3 more. Any additional cost of putting bling to jazz up the T-shirts will go to March of Dimes as well.



Save Around Greater Fresno 2016 Book Sales:

The saving coupon books are now on sale. will go towards March of Dimes.



The cost of the coupon book is \$20 each and \$10

Recyclable bottles/cans and glass bottles:

Team Neo Nurses will personally pick up your recyclables at your house. All proceeds will go to Team Neo Nurses and Friends. Also, we can go green with this special project as well!

Food Sales:

Many food sales activities will be underway soon. Stay tuned for more details!

Raffles:

Many baskets will be raffled out during the March for Babies-March of Dimes Walk. Such baskets include: skin care products, wine baskets, Hugry Hair Salon hair cut certificates, blankets, quilts, animals and many other items will be raffled off during this event. The cost of the raffles is \$5 each and 5 for \$20.

Valerie's Hair Cuts:

Valerie Johnson, HUC, will be donating her hair cut proceeds to our team. Go, Valerie!

Lastly, Team Neo Nurses and Friends invite you all to join us for the walk and bring in your individual sponsorship donation.

Thank you for participating to make a difference in our little Preemie's lives!!!

Sincerely,

Savath Sullivan, NICU Nurse
Team Captain, Neo Nurses and Friends



Community Service

Thank You CCANN!

From HRIF Clinic



The staff at the High Risk Infant Follow-Up Clinic at Valley Children's Hospital is dedicated to identifying developmental problems within the first three years of life in children who were in the NICU after birth and are at risk for developmental delays. We provide resources and referrals to help in these children's' growth and development. Approximately 200-240 of the patients we see each year are between the ages of 2 and 3 years old; this is typically their third and last visit. With the generous donations from CCANN, we are able to provide these children with a developmentally appropriate graduation gift. The toys that we give to the children include baby dolls, "push and go" cars and bouncy balls. These gifts are a big hit with the kids and are very much appreciated by our staff and the families; we could not provide these things without the help of CCANN. Thank you from the bottom of our hearts!

Sincerely,

HRIF Clinic Staff &

Leah Smith RNC-NIC, BSN, HRIF Clinic Coordinator



Thank You From Terry's House!

Thank you for your recent gift of \$350 to Community Medical Foundation in support of Terry's House. We really value donor-investors like you and aim to match your commitment with greater stewardship on our part. Terry's House, a hospital-ity home across the street from Community Regional Medical Center in downtown Fresno, is thriving and continues to provide families a place to stay while their loved one is recovering from severe illness or trauma injury. We are grateful for your support and invite you to call on us at anytime.

Sincerely,

Alexis Perez

Foundation Manager

Community Medical Foundation



Additional Community Service Donations from CCANN

Ronald McDonald House ***\$600***

Community Food Bank ***\$1000***

CCANN's Mission Statement:

The goal of NANN - Central California Chapter is to serve our community and bridge the gap between the various hospitals' nursing professionals in our valley. Neonatal nurses are uniting to serve and foster professional growth with a simple goal of providing excellent and safe care to the little ones we all love to care for.

Greetings CCANN!

Gilda Aum, RN, President

I hope everyone had a grand New Year's celebration. As we welcome 2016, CCANN would like to recognize and give honor to three amazing officers who had greatly contributed to the organization.

MaryAnn Imbing

As our outgoing president, *Maryann* has been a goal oriented, energetic and artistic individual. In her tenure, she has spearheaded the massive task of upgrading and modernizing our CCANN website. This has brought CCANN recognition in the area of communication, raising the bar to its newest heights. It has allowed us to reach out to all our members, sponsors and web site browsers more effectively. Also, it was on her tenure that CCANN received the 2015 NANN Chapter of the Year Award, as well as awards for best in Educational Offerings, Communication, Membership Recruitment and Retention, Advocacy, Community Services and Fundraising. What an achievement!

Nelfa Reynon

Nelfa is another leader CCANN is grateful for. She is our outgoing Treasurer who served from 2013-2015. She has shown admirable dedication and organization in her duties, working above and beyond her call of duty to manage our nickels and dimes. She also had a special talent in membership recruitment as well. She will be assuming the role of our 2016 recruitment officer.

Rachel Olsen Ewing

Rachel is our outgoing Secretary. *Rachel* has always been very diligent in her task; assuring meetings are effectively documented and recorded. *Rachel* also chaired the Marjaree Mason Fundraising campaign as her own community service project. Great job!

With much respect and appreciation for their various contributions to CCANN, we would like to extend our grateful appreciation to *Maryann, Nelfa and Rachel* for all their hard work. We wish you all the best in your future endeavors!



Fundraising

As our 2016 fundraising season begins, we once again have the popular Jamba Juice cards. The cards are very simple to use. Each card is good for 6 "buy one, get one free" smoothies and are redeemable at over 15 locations. **The cards are \$10 each and have a value up to \$35!** Fund-raising activities such as the Jamba Juice fundraiser, allows the chapter to provide members with low cost conferences, educational reimbursements, award scholarships, and help subsidize the costs of our holiday gala. The fundraiser alone allows the chapter to keep 50% of the profit. These Jamba Juice cards have NO EXPIRATION! So get yours from a CCANN member today!!!



The first \$500 of these proceeds went to support our poster child, Evie Goines!

CCANN's Sponsors



2015 CCANN's Christmas celebration was once again a blast!

By Hermelinda Bitcon, AKA: the dancing queen.

As evidenced by the photos, everyone was in their best holiday wear and the night proved to be of great fun.

These are some of the highlights:

We were entertained by our very own, king of comedy, *Greg Williams*. Tickling our funny bone and sharing stories about things that happen in our nursing experiences definitely sheds new and a funny light on some of the things we do daily. But the show doesn't stop there, Greg brings laughter to us about life in general. Thanks Greg! Great work!

Awesome hula and Polynesian performance by *Ashley Leyva*, and so beautiful! Those of us who have been to the Hawaiian Islands can really appreciate this great performance. The Tahitian dance totally floored me, this girl can move! Aileen and her husband showed their love and support by sitting in front row, as you could truly see the pride in their faces. Awesome work Ashley!

But the entertainment didn't stop there! Our very own, *Liz Ocanas* wowed us with her talented voice. Yes, this girl CAN SING! So impressive to hear the notes this girl can deliver. If you closed your eyes, you might think you were listening to the likes of Adele, among others. Thanks so much for sharing your talent with us Liz! You rock!

We also had some tears as *Shauna Bellflower* was presented with a monetary gift from CCANN. Battling the ugly disease that knows no discrimination has made our Shauna a warrior in pink. We love you Shauna, and you are truly a warrior!

Dinner was buffet style and delicious. The sweets were provided by *Kim Collins* and she outdid herself with the tasty and diverse spread! Where does she find time to do all this great stuff?

Dancing is always the highlight of the night for me, but enjoyed by all. I do believe everyone had at least once dance on their card. I had my card half-full this time. Will try harder next time! Let's not forget the raffles, it's always fun to buy tickets and see who walks away with the best raffle prize. But the best part is the designated recipient of the funds. This time the proceeds went to *Evie Goines*, our poster child, received in January, 2016.

Coming together as professionals to celebrate the holidays is a lot of fun and we create wonderful memories. Making time to prepare an event is not easy, it takes a lot of work and planning. The team shows up, the work gets done, and we truly enjoy our time together. Thanks to everyone in the CCANN for making this event a success, particularly *Maryann Imbing* and *Kamela Loo*, who are currently leading this association. It takes a village, and this team is definitely a village to be proud of.





**National
Association of
Neonatal
Nurses**

Central California Chapter

Advocacy



**Poverello
House**

By Gilda Aum, RN, CCANN President

2013-2015 Advisors & Officers

Advisors:	Indira
	Chandrasekar
	Jimmy Lan
	Michael Allshouse
Founder/Advisor:	Kamela Loo
President:	Gilda Aum
President-Elect:	Vacant
Secretary:	Kaye Jones
Treasurer:	Kim Collins
Membership:	Nelfa Reynon
Newsletter Publisher:	Karen McGough
Photographer:	Hermalinda Bitcon
Facebook, Twitter:	Leslie Williams
Instagram:	Jennifer Castaneda

Mike McGavin was searching ways to repay God for saving his life.

The divine answer came to him when he noticed the homeless people on the streets of Fresno. He gave them food, offered his time to them letting them know that someone cared for them. Soon other people started helping Papa Mike in his advocacy. He later on acquired a storefront building and named it after the place that saved his life when he was in San Francisco: Poverello House. Currently Poverello House is located in 412 F Street CA 93706. Poverello House offers Healthcare Services. The clinic provides free medical and dental care to the poor and homeless in our community provided they do not have an existing insurance. They also provide three hot meals a day for the entire year to those in need. They offer temporary shelter, social services and housing referrals. Indeed the Poverello House and its partner agencies have done so much goodness in our community. CCANN together with Savemart located in North Willow Ave. is handing over a total of 525.00\$ to Miss Stephanie Ortiz, Marketing and Communications Manager of Poverello House, to help them in the organization's advocacy.

*Anyone can be a part of this amazing story of hope and inspiration.
Visit www.poverellohouse.org if you are willing to make a change.*



Membership Recruitment

Stayed tuned for our recruitment campaign coming in March with a group discount! See Nelfa for details.



Chapter Awards

2015 NANN Chapter Of The Year Award

2014 NANN Chapter Community Service and Fundraising Award

2013 NANN Chapter Communication Award

2012 NANN Chapter Education Offerings, Fundraising, Community Services, and Membership Recruitment & Retention Award

2011 NANN Chapter of the Year Award

2010 NANN Chapter Communication and Education Offerings Awards

2009 NANN Chapter Communication Award

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<https://www.facebook.com/pages/Central-California-Association-of-Neonatal-Nurses/125767764241672>

We're on the Web!

www.ccannurses.com