

Public Affairs Press

Our Advocacy Efforts in California



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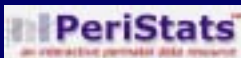
Resource Center



Southern California Chapter



Northern California Chapter



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Newborn Screening Special Issue

"The mission of the March of Dimes is to improve the health of babies by preventing birth defects and infant mortality."

Momentum

What a difference a month makes. In February we were wondering the next steps to expanding newborn screening in California. Some great things were on the horizon, but we didn't know how they would develop. Today we know, and we just turned the rest of 2004 on its ear.

After a successful hearing at the Capitol in February and another successful event at the Capitol, we put enough pressure on the state legislature to take action. Senator Dede Alpert of San Diego will soon introduce legislation to expand newborn screening from the four disorders we currently screen for, to more than thirty.

If you haven't been a part of changing law before, you're in for a fun ride. The March of Dimes will be working hand-in-hand with Senator Alpert to get this legislation passed. The role you play will be crucial to our success.

It will take a major effort from everyone across the state and nation to make this happen. And when it is over, you can sit back and know you were instrumental in changing a law that will save the lives of countless numbers of babies.

Newborn Screening

Senate Bill 142 (SB 142) — memorize that number and repeat it in your sleep. That is the bill that will move California back to the front of the pack in state newborn screening programs.

A month ago it looked like it would be at least another year before we even introduced legislation to expand newborn screening in California. Let me tell you how we turned things around so fast.

Informational Hearing

On February 24, 2004 we held an informational hearing at the Capitol around newborn screening. The hearing began with Dr. Cunningham updating the committee on the Tandem Mass pilot that ended last year. He reported that one child for every 6500 who participated in the pilot were identified with a detectable disorder. This is a total of 51 children (up from the original 41 we knew). Additionally, eight babies with a metabolic disorder that were not screened in the program have been identified. In the entire population of babies born in California during the pilot, it is estimated that 49 more babies have a detectable disorder, but did not participate in the pilot. We have no way of knowing who these children are until the disorder manifests itself during a crisis.

Click here to view the Newborn Screening legislative hearing online (requires Real Player)

Go to 02/24/04 Select Committee on Genetics



Statistically Speaking

One baby

out of every

6500

who participated in the Tandem Mass pilot program was detected with a metabolic disorder.

Source: Dr. George Cunningham, California Genetics Disease Branch

Visit this month's

website

highlight

Newborn Screening (Continued)

David Swift, a parent from Los Angeles, shared his story of how he initially refused the additional testing because he didn't want his daughter poked with any more needles, when he was told it would not take any additional "pokes" he changed his mind. That decision changed the life of his daughter who has one of the disorders Tandem Mass detects. Because she was identified, she has been put on a special diet and is living a relatively normal life.

Lisa Jaquez, a parent from San Carlos, shared her story about her daughter Ysabel. Ysabel was not screened and today is struggling with one of the disorders that could have been detected if California was using Tandem Mass when she was born. Lisa also went down the list of costs her family and the state have incurred in caring for Ysabel.

That was the end of the formal program. When the floor was opened up for public comment, something none of us could have scripted happened (I know, because I tried). The Black family, who were scheduled to testify at the hearing, but were late because they couldn't find the building, came forward to speak and sat at the table next to the Wyvill family who just wanted a moment to tell their story. Both families with a son named Zachary — both children with the exact same metabolic disorder. Zachary Black participated in the pilot and is living a healthy normal life. Zachary Wyvill was born in a hospital that did not participate in the pilot and is struggling with neurological disorders. Zachary Black was at the hearing with his piercing blue eyes and infectious smile. Zachary Wyvill stayed home with his nurse, but his twin brother Nathan attended. Nathan has shown no signs of the disorder his brother has, but has now been tested and is being treated as a precaution.

Several more families and individuals spoke on the value of expanding newborn screening in California. It was by far, the most emotionally draining day of my legislative years.

Legislative Summit

On March 11, 2004 the March of Dimes, Public Health Institute and Center for Disease Control held a legislative summit at the Capitol to update legislators on newborn screening across the country. Parents and groups from across the country were in attendance and participated in the daylong event.

At the end of another day filled with parents speaking about their experiences with newborn screening, State Senator Dede Alpert of San Diego stood up and announced that between the hearing in February and the events of that day, she had heard enough. She announced that she was immediately introducing legislation that would screen all babies in California for all detectable disorders.

Next Steps

Thank you to all the families who have been willing to tell their story at the State Capitol. We would not have made these great strides without their willingness to come forward.

The March of Dimes has been working with Senator Alpert's staff to introduce language that will allow this expanded newborn screening to be implemented as soon as we can. Now the real work lies ahead in passing the bill and making a new law in California. This is where we will need everyone's help. In the near future we will begin contacting legislators and raising their awareness of this issue. We have very creative things in-store and it will be fun watching this piece of legislation make its way through the process.

Quotable

"Laws are like sausages, it is better not to see them being made."

-Otto von Bismarck

Public Affairs Sleuth

- This person was born in Kuwait City, Kuwait
- Has been with the March of Dimes for 5 years
- Favorite March of Dimes moment was organizing a WalkAmerica Team comprised of about 100 students
- Favorite book is Tuesdays with Morrie
- Favorite food is vegetable fajitas
- Favorite color is **blue**
- Words of wisdom to share: "Love cannot remain by itself - it has no meaning. Love has to be put into action and that action is service." - Mother Theresa
- If this person could do anything, it would be to take different people around the world.
- Favorite Song: I Will Always Love You
- Favorite Movie: Goonies

Do you know who this person is? Click [here](#) for the sleuth solution.

Legislative Lookout

Bill	Author(s)	Assembly / House Committee	Assembly / House Floor	Senate Committee	Senate Floor	Conference Committee	Signed by Executive
Expanded Newborn Screening SB142	State Sen Alpert						
Newborn Screening: to establish a California NBS Advisory Committee SB231	State Sen Murray	PASS 7/8/03 22-0		PASS 4/23/03 12-0	PASS 5/22/03 37-0		
PREEMIE I: to provide premature birth research S1726*	Sen Dodd Sen Alexander	N/A	N/A				
PREEMIE I: to provide premature birth research HR3350*	Rep Eshoo Rep Upton			N/A	N/A		
PREEMIE II: to provide access to health care for pregnant women and infants S1734*	Sen Lincoln Sen Lugar	N/A	N/A				
PREEMIE II: to provide access to health care for pregnant women and infants HR3293*	Rep DeGette			N/A	N/A		

* = Federal Legislation

Do you know of legislation March of Dimes should be tracking or supporting? Contact Keith Nash, State Director of Public Affairs (916) 922-1913 or knash@marchofdimes.com

Mark My Words

- April 1-April 12, 2004 Spring Recess for the State Legislature
- April 24, 2004 WalkAmerica
- May 14, 2004 Governor's revised budget is released
- May 26, 2004 Capitol Day

If you have an event date, a statistic, or story to print in the Public Affairs Press, please send the information to [Keith Nash](#). All requests will be reviewed for publishing.



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