



# Special Parents Information Network

## Serving Santa Cruz County

Vol. 1 Issue 1

Fall 2001

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## Our First Year

By Mary Balzer  
President, Board of Directors

It is incredible that Special Parents Information Network -- SPIN -- is celebrating its one-year anniversary! It was one year ago that we became an OFFICIAL nonprofit organization, and became the first organization in Santa Cruz County that is devoted to helping children with special needs by helping their parents. That help comes in the form of networking and sharing information, providing individual phone support and support groups, educational meetings and events, and a parent mentor program. More about that later...



This first year of the new millennium has been filled with formalizing our structure, recruiting additional board members, getting our accounting and record-keeping procedures in order, working on a strategic plan, and getting lots of input from the special needs community! We conducted a survey early in the year to assess what is needed from SPIN, and how people might be able to help. We held an IEP training last May and sponsored a workshop with James May (Director of the National

Fathers Network) in October, along with our regular parent meetings. We got pledges and walked in "The Human Race" on West Cliff Dr. in April. Moss will not gather under our feet!

But the big news is that SPIN was awarded a \$50,000 grant in May from the Santa Cruz County Children and Families Commission. The County Commission is funded by the state of California Proposition 10 tobacco tax monies to improve conditions for children age 0 up to age 5. SPIN will do several things over a period of two years: develop a parent mentor program, produce and distribute a special needs resource directory for parents and professionals in Santa Cruz county, and coordinate several workshops and support groups for parents of children ages 0 to 5. We have hired a part-time project coordinator, Sheryl Wobber, and have leased a small office at the WIC building on Water St. to facilitate the success of this very important project.

The Prop 10 grant is definitely a positive turn of financial events. However, it is only for the 0-5 population and their families. We have so many other families with children in the other age groups, with many needs and challenges as well. SPIN has a tremendous amount of work to do. We need your help, whether it be with your time as a board member or other volunteer, your financial help, with a tax-deductible donation or in-kind services, or even as an informal public relations expert. Yes, spread the word to everyone you know that SPIN is real, it is up and running and is a resource for parents who have children with special needs in Santa Cruz County.

## **Philosophy of Parent Mentoring Program**

For most parents, having a child is a challenge. When the child happens to have a special need, the family may have an even greater need for emotional and other supports.

The emotions that may arise when parents find out their child has a disability or chronic health care condition, and the sometimes overwhelming plunge into a medical and/or educational whirlwind, can take away from one of life's happiest moments.

Looking back, many parents who felt isolated and overwhelmed feel it would have helped to talk with other parents who had gone through the same experiences and challenges. The goal of parent to parent support (parent mentoring) is to fill that void.

Our program is simple: parents of children with disabilities and chronic illnesses offer support to others in the same situation.

Support relationships develop in the direction indicated by the needs of the new parents. Mentor parents do not provide all the answers, but do provide insight into the issues new parent will face. Mentor parents can be role models by sharing their joy and pride in achievements of their own child.

It is a relationship based on "I know and I understand."

## **Mentor Parents Needed!**

Please fill out and send in the attached form if you are interested in being a mentor parent. Future trainings are planned. For more information call SPIN at (831) 425-3428

## **The Impact of Parent to Parent Support**

These are the results from a national study to determine the effectiveness of parent to parent support, directed by Dr. George Singer, University of California, Santa Barbara:

- **Parent to parent support increases parents' sense of empowerment.**
- **Parent to parent support increases parents' acceptance of their situation.**
- **Parent to parent support increases parents' sense of their own capacity to cope.**
- **Over 80% of parents found parent to parent support to be helpful.**
- **There is a strong relationship between the number of contacts a parent has with a mentor parent and how helpful the parent found the mentoring program to be.**
- **Interviews suggest that the kind of support parent to parent offers is unique and probably cannot come from any other source.**
- **Therefore, it is one essential component of a comprehensive family support system.**

For additional information or a copy of the study, please contact Beach Center on Family and Disability (913) 864-7606

### **TIPS FOR SUCCESSFUL PARENT –PROFESSIONAL RELATIONSHIPS**

Trust, respect, and open communication between parent and professional are essential to building a good, working relationship. This can take time to develop and may require effort from both parties. To that end, many parents suggest:

- \*\* If you are looking for a specialist with whom you can work well, ask other parents of children with disabilities.
- \*\* If you don't understand the terminology a professional uses, ask questions. Say, "What do you mean by that? We don't understand."
- \*\* Learn as much as you can about your child's disability or disorder. This will assist you with your child, and it can help you participate most fully in the team process.
- \*\* Prepare for visits to the doctor, therapist, or school by writing down a list of the questions or concerns you would like to discuss with the professional.
- \*\* Keep a notebook in which you write down information concerning your special needs child. This can include your child's medical history, test results, observations about behavior or symptoms that will help the professional do his or her job, and so on. (A loose-leaf notebook is easy to maintain and add information to.)

## FINDING INFORMATION AND SUPPORT ON THE WEB

The abundance of information and support currently available on the WEB is mind-boggling... Please feel free to contact SPIN if you need help navigating the WEB. To find information regarding your child's specific conditions or needs. Please visit SPIN's website at [SPINSC.org](http://SPINSC.org).

### INTERNATIONAL PARENT TO PARENT CONFERENCE 2002

Philadelphia, PA

April 5-7, 2002

(Pre-conference day April 4th)

This biennial Conference is one of the largest conferences of parents and families in the United States. For more information call **717-540-4722** or check it out on the WEB at: <http://www.parenttoparent.org/2002.htm>

#### Parents and Professionals

Join us for an information night on SPIN. This evening will include a parent panel and discussion on the joys & challenges of raising special children.

**Dominican Hospital**  
Rm. B-2  
Monday, October 15  
7-9 PM

#### Conference Opportunity

##### Parents Helping Parents—Santa Clara “BUILDING CARE TEAMS FOR CHILDREN”

October 18, 2001

9:00 a.m. to 5:00 p.m.

- The National and Local Perspective of Family Centered Care
- How the Project began/Steps in the Process
- The Medical Provider Perspective
- The Parent Liaison—the Link between Families, Hospitals and Community
- The Family View

Friday, October 19, 2001

9:00 a.m. to 5:00 p.m.

- Family Resource Center—Setting Up: the Nuts and Bolts
- Creating the Partnership
- Training Strategies and Relationship Building
- Providing Services to Families and Evaluating Success
- Negotiating Funding: Life After the Grant
- Integration & Synthesis
- Site Visits

#### FEES:

Professional .....\$200  
Families.....\$170

FOR MORE INFORMATION CALL PHP AT  
**(408) 727.5775 OR visit their web site at**  
<http://www.php.com/family2001.htm>

#### Parent Mentor Sign-up

I/ We are interested in being a parent mentor for SPIN. I/ We have read and understand SPIN's goals and philosophy of parent mentoring. Please complete this form and return it to P.O. Box 2367, Santa Cruz, CA 95063

Name(s): \_\_\_\_\_

Street Address: \_\_\_\_\_

City: \_\_\_\_\_ ZIP: \_\_\_\_\_ Telephone # / Email address: \_\_\_\_\_

How many disabled children: \_\_\_\_\_ My child's(ren's) disability(ies) is/are: \_\_\_\_\_

Birthdate(s): \_\_\_\_\_ School District attending (optional): \_\_\_\_\_

Profession and/or special interests (optional) \_\_\_\_\_

Please check one of the following options:

- SPIN has my/ our permission to give out our phone number to any family who may need support.
- I/ we would like SPIN to contact us first and discuss whether it would be appropriate and/or a good time for me/us to provide support to another family.
- SPIN is also in need of help and support. Please check any of the following
- I /We would like to be a volunteer. My skills include the following \_\_\_\_\_
- I/We would like to donate the following amount \$ \_\_\_\_\_ SPIN is a 501(c)(3) nonprofit charitable organization

## **EXTRA EXTRA--READ ALL ABOUT IT!! SPIN SEEKS YOUR SUBMISSIONS**

SPIN seeks **your** contributions to our quarterly newsletter! Writers or aspiring writers please send us your stories, or informational articles pertaining to children with special needs. Article topics can include but are not limited to the following: 1- Parenting; 2- Health care; 3-Education; 4-Traditional and complimentary care; 5- Family/community issues; 6-Advocacy. SPIN reserves the right to edit articles submitted. E-mail submissions to DanaRN@aol.com. We will also include and seek submissions for the following columns:

- **SEARCH & RESPOND**: This is an opportunity for parents and/or professionals to exchange information about their practical experiences of raising and/or working with a child with special needs.
- **WANT ADS**: This is an opportunity for families to seek, sell or give-away toys, equipment, and other items that may benefit another child.
- **LEGISLATIVE UPDATE**: Share with other families information regarding local, state and/or federal legislation pertaining to health care, education, and/or disabilities. Please include ways parents may advocate and or contact their appropriate representatives.

### **A Short History of SPIN:**

SPIN had its beginnings 15 years ago as a group of mothers who met to talk about the challenges of raising a child with disabilities, In 1995 the group became Parents Helping Parents of Santa Cruz, under the leadership of Lynn Bariteau. This group was under the fiscal umbrella of Parents Helping Parents-Santa Clara, and began more outreach, phone support, sponsoring weekend retreats for mothers, holding monthly educational meetings, and IEP workshops for parents.

For the past sixteen years, every activity, event and workshop for parents has been conceived and produced by parent volunteers. This was a true grassroots organization. In 1999, a small group of moms decided that it was time for the organization to formalize and have enough structure to withstand the waxing and waning of a few people's energy. They tackled the Federal and state of CA nonprofit (501-c3) applications, meeting week after week for a year, and were rewarded for their efforts with SPIN's official nonprofit status in June 2000.



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