



# The *Gathered View*

National Newsletter of the Prader-Willi Syndrome Association (USA)

## Prader-Willi Syndrome Added to Wisconsin Statutes — We Did It!

by Barb Dorn, Executive Director  
Prader-Willi Syndrome Association of Wisconsin, Inc.

On Monday, December 15, 1997, friends, family members, and persons with Prader-Willi syndrome (PWS) gathered in Madison, Wisconsin, the state capital, to watch Governor Tommy Thompson sign Assembly Bill 403 into law. This signing added PWS to Chapter 51 of the Wisconsin statutes, which defines "developmental disability." This addition provides clarification for those service providers who are not familiar with PWS and will make it easier for *all* persons who have PWS to receive the necessary evaluations and services that they need to live and work in our communities.

Over the past few years, our chapter has had isolated cases in which persons with PWS were denied access to evaluations because they were "not mentally retarded." After advocating and informing these providers, our office was able to secure services for them. The confusion occurs because 40 percent of persons with PWS do *not* have mental retardation. They *do*, however, receive treatment and supports as if they were. (This statement is taken directly from our state's definition.) It is those individuals who often ran into delays when trying to access residential and/or vocational services.

According to the State of Wisconsin statutes, Chapter 51, a developmental disability means "a disability attributable to brain injury, cerebral palsy, epilepsy,



Wisconsin chapter officers pose at the state capitol following their victory. From left: Treasurer Tom Scheidegger, President Mike Larson, Vice President Jenny Lucas, Secretary Pat LaBella, and Executive Director Barb Dorn.

autism, mental retardation, or *condition closely related to mental retardation or requiring treatment similar to that required for mental retardation, which has continued or can be expected to continue indefinitely and constitutes a substantial handicap to the affected individual.*" Persons with PWS have always met the state definition, but those who did not have mental retardation often had hurdles to overcome before receiving the help they needed. Now there should be no more hurdles. PWS has been

added to the list.

In 1995, the Bureau of Developmental Disabilities Services and PWSA of Wisconsin, Inc., collaborated by disseminating information about the disability as well as by clarifying that these individuals *did* in fact meet the definition. On February 10, 1995, Secretary Gerald Bourne distributed a memo to service providers across Wisconsin. Things improved ... for a while. Then, however, we started to receive calls again.

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## The Prader-Willi Syndrome Association (USA)

5700 Midnight Pass Road, Suite 6  
Sarasota, Florida 34242

1-800-926-4797

Local: (941) 312-0400, Fax: (941) 312-0142  
9:00 a.m.-7:00 p.m. Eastern Time

### PWSA (USA) on the Internet:

[www.pwsausa.org](http://www.pwsausa.org)

E-mail: PWSAUSA@aol.com

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<http://www.pwsausa.org>

*And we're adding more information,  
news, and resources every week ...*

*Don't forget our live chat room—it's buzzing  
with conversation on Wednesday nights!*

*(accessible with Java-capable Web browsers)*

### Wisconsin legislation *(continued from page 1)*

In 1996, our organization approached two legislators, Senator Joe Wineke and Representative David Brandemuhl, requesting their support in adding PWS to Chapter 51. It seemed like the only way to guarantee services for persons with this disability.

Dr. Thomas Hughes and Barb Dorn began their journey in working with these legislators to do the things that were needed to make this process a success. Meetings were held, testimonies were given to both the senate and assembly health committees. Representative John Lehman from Racine found this legislation near and dear to his heart. It was through this process that we discovered that he is the father of a young woman with PWS. He candidly shared his personal story with his colleagues and testified about the experiences he faced in securing services for his daughter. Pat LaBella also contributed to testimony. It became a real family venture.

The journey was long and a real learning experience, but ... we did it! We have surely increased awareness about Prader-Willi syndrome as well as made a significant change that will benefit ALL persons who have it. Wisconsin, you have a lot to be proud of.

**The Gathered View** (ISSN 1077-9965) is published bimonthly by the Prader-Willi Syndrome Association (USA) as a benefit of membership. Annual membership dues are: \$30 Individual, \$35 Family, and \$40 Agencies/Professionals for U.S. members and \$40, \$45, and \$50 (US Funds), respectively, for members outside the United States.

Opinions expressed in *The Gathered View* are those of the authors or editors and do not necessarily reflect the views of the officers and board of directors of PWSA (USA). *The Gathered View* welcomes articles, letters, personal stories and photographs, and news of interest to those concerned with Prader-Willi syndrome.

Editor: Linda Keder, Silver Spring, Md. (e-mail: [keder@erols.com](mailto:keder@erols.com))

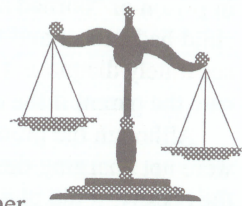
Associate Editor: Lota Mitchell, M.S.W., Pittsburgh, Pa.

Communications regarding *The Gathered View* or PWSA membership and services should be directed to the national office of PWSA (USA), 2510 S. Brentwood Boulevard, Suite 220, St. Louis, MO 63144-2326. Telephone 1-800-926-4797, or, in the St. Louis area (314) 962-7644. Fax (314) 962-7869. E-mail: [pwsausa@aol.com](mailto:pwsausa@aol.com).



## **The Christina Corrigan Case: Who Should Be On Trial?**

by Janalee Heinemann



**I**n late October I received calls from two PWSA members about a CBS show that had featured a mother charged with "child endangerment" due to the death of her 13-year-old daughter who weighed 680 pounds. Both said, "This has got to be PWS!" A few days later, while waiting for a callback from a San Francisco reporter whose story had launched the CBS piece, I received calls from parents in four different states regarding another national show featuring Marlene Corrigan and her attorney, Michael Cardoza. Elizabeth Fernandez from the *San Francisco Examiner* returned my call and gave me Mr. Cardoza's phone number. When he called back the next day, Cardoza said, "I was praying that our media coverage would result in bringing someone like you to the foreground."

Thus began an intensive month of almost daily calls, consultations, mailings, and networking. Other PWSA members became involved as well, included Fran Moss, PWSA board member from California and executive director of the Prader-Willi California Foundation, and Doctors Bryan Hainline, Suzanne Cassidy, and Dan Driscoll.

After many discussions by phone, and reading our materials, Defense Attorney Cardoza felt that my testimony (as a social worker, parent, and executive director) and Dr. Hainline's testimony (as a specialist with PWS and metabolic disorders in general) would be important. Marlene could not afford to fly us to California, so the board approved funding through PWSA's CIT (crisis intervention and training) fund. Marlene Corrigan was extremely grateful. I was able to spend time with her as well as her son, a very nice young man in college.

### **The 'Facts'**

At this point, I have read and heard a couple dozen versions of "the facts" in this case, so would like to share what I

know to be the facts.

- Christina's mother says that her daughter's weight started going up dramatically at around age 3. Although she was gaining weight at an alarming rate, and her mother took her to the doctor and to a dietitian 90 times, the only test ever done on her was a thyroid test. She was never sent to a specialist. The dietitian also provided no other support than to put her on a typical diet and watch her weight go up weekly. Several years ago, Christina refused to go to the doctor anymore, and her mother gave up trying to take her.

- Christina appeared to be normal in IQ but had no testing that could verify it. She had problems with sleep apnea and frequently fell asleep during class. The doctor said she would outgrow it. When Christina was to begin middle school, a year before she died, she told her mother she could not walk up the hill to school. When Marlene called the school to discuss the problem, she was told that because obesity was not considered a disability, they were not required to make special accommodations. Marlene requested a home tutor but was denied school services. The school did not notify either a truant officer or any social service agency during the entire year Christina did not attend school. So Christina stayed home, isolated, but protected from the stares and cruel comments of classmates.

- Although the prosecuting attorney portrayed Marlene as a neglectful mother, the reality is that she is a single parent who has held the same job over 20 years, was caring for both parents, then running home to care for Christina. Her father died a month before Christina, and her mother a month after. According to her attorney (in a private conversation I had with him), their home

Christina Corrigan was just 13 years old in November of 1996 when she died of heart failure due to obesity — she weighed 680 pounds. This past December, Marlene Corrigan was put on trial for child endangerment, not because of her daughter's weight but because of her living conditions and particularly her "bedsores." Although Christina had never been diagnosed with Prader-Willi syndrome, PWSA became involved in her mother's defense when the trial hit the national media. PWSA Executive Director Janalee Heinemann and Dr. Bryan Hainline, a PWS expert from Indiana testified at the California trial regarding the unique characteristics of people with PWS and PWS-like conditions. After a five-day nonjury trial, Marlene Corrigan was convicted January 9 of misdemeanor child abuse, rather than the felony charge that could have sent her to prison for six years. She now faces a maximum of one year in jail, to be decided at her February 27 sentencing.

Janalee reports on the case on pages 3 and 4 of this issue.

### **DID CHRISTINA HAVE PRADER-WILLI SYNDROME?**

We will never know. There were no tests done while she was alive, and no autopsy was done, even though Marlene had requested one. Christina's mother and her 22-year-old brother report that she had many of the classic PWS features, including all of the behavioral problems, incomplete pubertal development, decreased fetal movement, skin picking, sleep apnea, thick saliva, articulation defects, high pain threshold, altered temperature sensitivity, and unusual skill with jigsaw puzzles.

The primary characteristic she was missing was that she was not the classic "floppy baby." We do know that if Christina did not have PWS, she was at least "PWS-like," with a similar brain dysfunction. At PWSA-USA, we frequently get calls from parents dealing with "PWS-like" symptoms and problems. If we don't help these families, who will? Marlene has told me that what haunts her the most is that perhaps if she had known about our association, Christina might still be alive. —JH

(Continued on page 4)



(Continued from page 3)

was not in the deplorable condition portrayed. Christina did have sores on her body but was very private about exposing herself to her mother. The sores on her body and the question regarding whether they were painful were significant in the testimony. As we are all aware, with PWS, many of the sores could have been self-induced and not painful. After looking at the pictures presented in court, both Dr. Hainline and I felt that many of the sores were typical of picking sores of children with PWS and were not "bug bites and bed sores," as reported.

### **The Media**

The night before I left for the trial, Elizabeth Fernandez called back (after receiving my packet on PWS) and did a phone interview, plus contacted three California families — the Youngs, La-Bossieres, and Larsens. The story was featured on the front page of the Sunday *San Francisco Examiner* (12/21/97). Monday, while waiting outside the courtroom, I was able to hand our packets on PWS to eight reporters and discuss the syndrome with them. I was interviewed by three television stations, and Dr. Hainline was also interviewed and quoted (and as always, misquoted) by several reporters when he went to testify a week later. David Penn and I have been inundated by calls, faxes, and e-mails from around the world. Also, Fran Moss reports that the California Foundation received 21 calls the day after I testified and continues to get calls. This case, and word about Prader-Willi syndrome, has been on more television shows and in more newspapers than I can mention here.

### **The Prejudice**

One of the saddest aspects of my trip was having to really look at the subversive hostility and aversion the general population has towards obese people, which was brought to the surface by this case. An example was when I was sitting outside the courtroom before anyone knew who I was. A reporter came out of the courtroom to talk to the camera man. (Cameras were banned from the courtroom.) He said to her, "Is this on that fat girl? Her mother ought to be burned at the stake!" My personal question is:

Why is it that we allow so many hardened criminals to roam our streets, yet feel that this passive mother, who was a victim of society and life circumstances as much as her daughter, should be put in prison or "burned at the stake"? If a child had cancer and the doctor did not accurately diagnose it, would we prosecute the parent if the child died?

Although the prosecutor said they were not charging the mother because of the obesity, it did play a major factor in attitudes. As for the condition of Christina's body and the room, how many parents of an older child with the syndrome really know what condition their child's body is in? Our son Matt, like many older children/adults with the syndrome, learned to pick in areas of his body we could not see. As far as the condition of his room — I would rather not comment for fear of incriminating us! This case was a humble reminder to me that we have a long way to go in the awareness, understanding, and acceptance of PWS and "PWS-like" obesity-related conditions.

### **The Outcome**

The defense attorney was able to get Dr. Hainline and I admitted as expert witnesses and was very pleased with our testimony.

On January 9, 1998, Judge Richard Arnason ruled that Marlene Corrigan was not guilty of a felony as charged, but of a misdemeanor. He said, "There is

absolutely nothing in the record from which it can be factually determined or even inferred that the defendant knew or should have known that her conduct or failure to act was likely to produce great bodily harm or death."

In a letter to the PWSA Board of Directors, Michael Cardoza states: "Your generosity in allowing Ms. Heinemann and Dr. Hainline to testify was the reason we were able to successfully defend Ms. Corrigan against the felony charges. Their testimony was the highlight of the trial. I have over 20 years' trial experience ... and in all those trials I have rarely seen such compelling testimony."

In talking to Marlene after the decision, she said that if anything good comes out of this, it will be the awareness of Prader-Willi syndrome and "PWS-like" disorders. She said of her son that "he misses Christina tremendously, like I do." I have sent Marlene bereavement information, and she knows we are here for ongoing support. Although I cannot give out her address, anyone who would like to write her a letter of support or just send a card can send it in care of PWSA, and we will forward it to her.

I want to thank all those who called or sent information to us on this case. As I have said in the past, "We are in this boat together." Bless you for caring.

*[Note: We've alerted PWSA Chapter presidents about Marlene's sentencing date and the possibility of parents writing letters to the court in her behalf.]*

## **Call for Nominations PWSA Board of Directors**

For the July 1998 elections, the Nominating Committee requests that names of members interested in, or recommended for, a seat on the PWSA (USA) board of directors be submitted to the committee no later than April 1, 1998. Recommendations should include a brief description of the member's qualifications to serve on the board.

Send recommendations by mail, fax, or e-mail to the attention of the Nominating Committee Chair, c/o PWSA (USA), 5700 Midnight Pass Rd., Suite 6, Sarasota, Florida 34242.

E-mail: [PWSAUSA@aol.com](mailto:PWSAUSA@aol.com)

Fax: 941-312-0142



**Plan now** to come to  
**"The Heart of It All"**

for the national conference of PWSA (USA), which will be held at the Adams Mark Hotel in Columbus, Ohio, July 23-25, 1998. This conference will have something for everyone. See old friends, make new friends, meet and learn from the experts, share your experiences with your peers, and in the process, help yourself and help others who are dealing with similar issues and experiences.

About half our speakers are from Ohio (a state which is blessed with expertise in Prader-Willi syndrome), and half are from outside the state, including speakers from Florida, California, New York, Boston, Pittsburgh, Iowa, Missouri, and Nashville.

Among this year's conference highlights:

- **Dr. Martin Ritzen**, an internationally recognized endocrinologist from Stockholm, Sweden, will present the results of the European multicentered controlled clinical trial of growth hormone therapy for Prader-Willi syndrome.

- **An exciting conference program** covering both "hot" topics—such as new developments in obesity management and prospects for new therapies, including gene therapy—and practical skills to take home, from early intervention to behavior management to dealing with managed care.

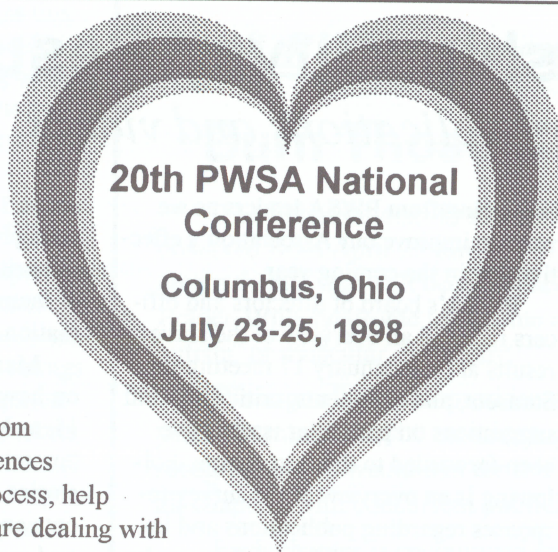
- **A "Meet the Speakers Room,"** where speakers will go after their session to meet with you and answer questions.

- **Opportunities for parents and their young children** with PWS to work with physical therapists, occupational therapists, and speech therapists.

- **A Youth and Adult Activities Program (YAAP)** professionally coordinated by the organization Joshua's Friends, led by John and Debby Stallings fresh from the Orlando conference's success. Among the special activities planned for registrants are clowns, storytellers, movies, a puppet show, a demonstration of zoo animals, a magician, a Tai Chi demonstration, bowling, a session for teenagers and adults to meet and talk about important issues, karaoke singing, a chance to make a record, swimming, folk dancing, a trip to the Columbus Museum of Science and Industry, a chance to meet famous football players from Ohio State, special makeup sessions, special activities for siblings, and—of course—a great banquet and dance.

**Conference registration packets will be mailed  
to PWSA members in March.**

Watch *The Gathered View* for conference updates. If you need advance conference information or want to volunteer to help, please call Conference Co-chair Pat Shiley at (216) 741-6778 or e-mail: PWSAOhio@aol.com.



**Announcement**

**13th PWSA  
Scientific Conference**

The annual PWS Scientific Conference, held in conjunction with the 20th Annual PWSA (USA) National Conference, will be held in Columbus, Ohio, on Wednesday, July 22.

The organizers of the Scientific Conference this year will be Dr. William Zipf, a pediatric endocrinologist from Ohio State University with long interest and expertise in PWS, and Dr. Suzanne Cassidy, a clinical geneticist from Case Western Reserve University in Cleveland who is chair of the Scientific Advisory Board of PWSA (USA).

The Scientific Conference is an opportunity for those who are conducting research on PWS—whether medical, basic science, nutritional, behavioral, or in another area affecting the condition—to exchange ideas and develop collaborations.

We are in the process of revising the mailing list for the Scientific Conference and are interested in identifying all individuals who might attend this conference, particularly those who are conducting research on the disorder and might present their work at the conference.

If you know the name and address of anyone who should be on the mailing list for the Scientific Conference, whether or not they are likely to submit an abstract, kindly send that information to PWSA (USA) either by fax (941-312-0142) or by e-mail (PWSAUSA@aol.com).

If you do not have access to fax or e-mail, please call 1-800-926-4797.



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**Prader-Willi syndrome (PWS)** is a birth defect first identified in 1956 by Swiss doctors A. Prader, H. Willi, and A. Labhart. There are no known reasons for the genetic accident that causes this lifelong condition which affects appetite, growth, metabolism, cognitive functioning, and behavior. The Prader-Willi Syndrome Association (USA) was organized in 1975 to provide a resource for education and information about PWS and support for families and caregivers. PWSA (USA) is supported solely by memberships and tax-deductible contributions.

