



# THE WISCONSIN CONNECTION

*The Newsletter of the Prader-Willi Syndrome Association of Wisconsin, Inc.*

**Mission:** The mission of the Prader-Willi Syndrome Association of Wisconsin, Inc. is to educate and assist families and professionals in dealing with individuals with Prader-Willi Syndrome.

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## LEGISLATIVE UPDATE

by Barb Dorn

Over the past few months, Dr. Tom Hughes and I have approached legislators to sponsor a change in Chapter 51 of the Wisconsin statutes which defines a developmental disability. We have asked that Prader-Willi syndrome be added to the list of disabilities in this statute. Senator Wineke and Representative Brandmuehl have agreed to sponsor both a Senate and Assembly bill. In the Senate it is bill #175, and at this time, there is not a bill number in the Assembly.

### So Why Do We Want to Do This?

It is estimated that 40% of persons with Prader-Willi syndrome are not mentally retarded. Mental retardation is often the criteria used by many professionals in determining whether or not a person qualifies for services. These services may be needed for both children and adults. Many of these services allow the person with Prader-Willi Syndrome to access funding sources to support them in their home or community. If the professional is not aware of this disability and its "neurological component" which has made Prader-Willi Syndrome meet the state definition, that professional could deny services and funding sources to the person with Prader-Willi Syndrome.

This situation has occurred and our office has been instrumental in informing the professional about Prader-Willi Syndrome so that these individuals were able to receive services. We worry about the situations that we haven't heard about. Our goal is to secure services for all persons with this disability without parents and/or care providers having to

spend many hours advocating (and arguing) for these services.

Last month you received a letter from our office asking you to contact your senator and your representative to vote in favor or these bills. It is important to contact BOTH. PLEASE, this could be one of the most important letters and/or phone calls that you will make. With your help - we can make a difference!!

### So What Do I Do?

You will need to either call or write to your legislators.

1. If you call, contact the LEGISLATIVE HOTLINE 1-800-362-9472
- a. Identify yourself and where you are from ("I am Barb Dorn from Verona...")
- b. State what you want (I would like Senator Wineke to vote YES on Senate Bill #175 and Representative \_\_\_\_\_ to vote YES on Assembly Bill to add Prader-Willi syndrome to Chapter 51 of the state statutes.

(Continued on page 2 See **Update**)

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## Notes from the President

### Mike Larson

It seems that volunteerism is a hot term the past month or so. Three presidents of our nation sponsoring a conference to bolster awareness of how important it is to get involved. Why do it? This is a question that gets asked many times. **For PWSA of WI, it would not exist if not for volunteers.** Luckily we have a few people who generously step forward and ask "what can I do to help make a better life for persons with PWS in WI?" Again we see this across the nation for PWS. Each state chapter has a few people that carry the torch, giving of themselves to help. I have asked others why they do it. The two most common answers are, "If I don't, who will? It needs to be done." and a second and similar response is, that they are scared of what will happen to their children when they, as parents, are no longer living or able to take of their childrens themselves. Who will help protect their interests?. Who will assure their living standards are acceptable and safe? Who will be continuously looking to uphold their safety and look for abuses of the system and abuse of people? (yes, this happens too).

This frightens me. As a parent maybe I have become a control freak and I'm always trying to protect my child. But behind my protection I realize I will not always be here to fight for him. What then? Will he be able to care for himself? Will he be able to know if he is getting the benefits he is entitled to? Is there additional funding available for medical care that is not covered by the "system"? Will he be able to find the right person in the "system" when he needs to get medical care? When he is wrongly rejected by the "system," will he be able to appeal through the maze of bureaucracy?

Are you willing to bet your loved ones life on all the programs of the state and federal government to run smoothly? Can you be assured that when you can't take care of your loved one, someone will be there to pickup from where you leave off? That's why it is important for you to become involved. We need people who are proactive and not willing to sit back and let things happen to them. We want to help shape the future for all persons with PWS. They have a right to live as full a life as possible. And they will not be able to do that without you.

How can you help?

- Join the state and national organizations
- Go to the local support meetings
- Volunteer to help organize activities sponsored by PWSA of WI.
- Call your state Senate and Assembly representatives asking them to vote for the PWS legislation.
- Ask the state office how you can help!

There is much to do and we need you!

## Update (Cont. from page 1)

We included a map with your legislators area of coverage along with their names and addresses. All you need to do is locate your city and see who the corresponding senator and representative is.

If you write a letter, the process is about the same as a phone call but you may want to include a picture or share a little something personal about your loved one.

### 1.) State who you are.

I am Barb Dorn, the parent of a 12 year old son who has Prader-Willi Syndrome. I am Joe Smith, the case manager for 2 adults who have Prader-Willi syndrome. I am Granny Smith, the grandmother of a 3 year old girl who has Prader-Willi Syndrome.

\*\*\*Make sure you spell out Prader-Willi Syndrome because your legislator will not know what PWS is.

### 2.) State what you want.

I am asking you to vote YES for Senate Bill #175 (and Assembly Bill #000) which will help clarify that people with Prader-Willi Syndrome qualify for services. Or. -- that will help people with PWS receive services faster and easier-

THIS LEGISLATION WILL NOT COST THE TAX PAYERS MORE MONEY. IT WILL ONLY HELP CLARIFY TO PEOPLE WHO DO NOT KNOW ABOUT PWS THAT THESE PEOPLE DO IN FACT MEET THE STATE DEFINITION or A DEVELOPMENTAL DISABILITY. (\*\*You can include this statement as well)

Most important, sit down and DO IT!! We need your help. Your letter and/or phone call will make a difference. We need you to speak for all our children so that services won't be denied or slowed.

The officers have put together packets that we have already begun to distribute to legislators. We will also use these to present before legislative committees and at legislative hearings. We still need you to speak to your legislator on your child's behalf.

If you have any questions, please contact Barb Dorn at the WI state office (608)-845-9597. If you are able to help us speak before a committee, let us know. We don't yet know the dates or times (and often we are only given 24-48 hours notice) It would look great if we had a small group go before them. (We can arrange it that you won't need to speak if you don't want to)

Be prepared, we will be contacting you soon- WE NEED YOUR HELP.

## Imagine... What it would be like if you were born with Prader-Willi Syndrome.

Teresa Kellerman (Prader-Willi Arizona Association)

*Teresa agreed to share this piece she wrote that appeared the Prader-Willi Arizona Association Web page and in their newsletter the Prader-Willi Nilli News. Thank you to Teresa and for her work with the Arizona association.*

**I**magine that your desire to get food is so strong that you would do ANYTHING to get it, even crawl out of your bedroom window in the middle of the night to walk to the store several miles away.

Imagine that you are hungry all the time, and that you are on a diet, all the time, and that you can only eat about half as much as everybody else, not to lose weight, but just so you don't gain weight. Imagine that if you do gain weight, you will have to go on an even stricter diet, getting about as many calories in one day as there are in just one cheeseburger and fries. Boy, would you like to have a cheeseburger and fries! But that's not in your diet. You are told that your diet is very important, because if you gain weight you could get really sick and die, because your heart can't handle the burden of obesity. Imagine that everybody in your group is going on a hike, and you want to go, but you know you will get tired easily, because your muscle tone is not really good, but you don't want to be left behind, so you go along, and it's really hard for you to keep up with everybody. And when you stop for lunch, the person next to you has a big sandwich with mayonnaise and cheese and roast beef and five cookies and potato chips, and the person sitting on the other side of you has 3 granola bars and trail mix with nuts and a candy bar. And you have two skinny slices of diet bread with mustard and a thin slice of ham, and a rice cake, and a teeny apple. You think that candy bar looks really good, and you watch that candy bar, because maybe it will get set down, and maybe you can get your hands on it, and maybe it would taste soooo good, and you can't think about anything else but that candy bar.

Imagine that you find a \$20 bill laying on the ground, and you pick it up and put it in your pocket and don't tell anybody, because maybe you can buy some candy bars with it some time when no one is looking. But you get found out and you are accused of stealing, and nobody believes that you just found it.

Imagine that when you see a little scab on your arm, you just have to scratch it, you can't help it, you just have to! And when it bleeds, you get in trouble. And you try really hard to leave it alone, but you can't! And sometimes it takes over a year for sores to heal.

Imagine that when you want something to eat you have to

ASK, and then you usually get told NO or you get carrot

sticks, and you can't eat what you want because there is a lock on the refrigerator and on the pantry too. But you know if there were no locks, you would get more food, and gain weight and get sick. So you really don't mind if the food is locked up. At least you don't have to worry about getting food like you used to before there were locks, and you would wait until the middle of the night to get up and go get food without anyone knowing. You feel safe with the food locked up.

Imagine that there's something you like to do and you're really good at it, like working jigsaw puzzles. And you have one that is a THOUSAND pieces, and you've been working on it for days, and you want to put it together all by yourself, because it's YOUR puzzle and you know where all the pieces go, and then someone else puts pieces in for you, and you take it all apart to start over, and you get yelled at, and you are told you are STUBBORN, but it's YOUR puzzle, and you just want to work it yourself.

Imagine that you are going to the movies, and everybody else is getting popcorn and candy, but you can only have a diet pop, but you have to sit there and smell everybody else's popcorn and chocolate, and watch them eat, and hear them munch. You really wish you could have a giant tub of popcorn like that guy over there! And you see a piece of popcorn that someone dropped and you pick it up and someone tries to grab it from you but you are faster than they are and you eat it, and they get mad at you, but it was worth it because that one little piece tasted so good. Better than the air popped stuff.

Imagine that you have a hard time expressing your feelings and you get mad easily, but only when things aren't fair. Only when someone breaks a promise. Only when you're not getting what you think you need or deserve. Imagine that when you can't say what you want to say and you scream and hit. You wonder why you get in trouble for hollering when everybody else is hollering too! Or sometimes you just sit and REFUSE, and nobody can make you move. You know you feel better when you take your medicine, but you don't want to take your medicine. You don't know why, you just don't want to take it. When you refuse to take your medicine, you get in trouble. But when someone in charge forgets to give you your medicine and you lose control, then you are the one who gets in trouble.

Imagine that you have family and friends who understand you. Imagine that your teacher, your case manager, your care provider, your doctor, all understand PWS. They know you are different, but they know you are special too. Imagine how lucky you would be!

(Continued on page 7 See **Imagine**)

## 1997 PWSA of WI MEMBERS

Listed below are the 1997 membership list for Prader-Willi Syndrome Association of Wisconsin. If you haven't paid your membership yet it's not too late. Just send your membership fee of \$12 to the State office. Make your checks payable to PWSA of WI. As always, if you can't afford the membership fee we have sponsored memberships. Just check the appropriate box on the form below. **We need your support! Please join today.**

Lorraine Ablor	Lori and David Fay	Janet Marcou
Scott & Janice Adams	Bob & Teresa Fischer	Joyce McNamar
Agape of Appleton, - Lee Bishop	Eric Fowler - Waisman Center	Laurel Mills
Sam & Sue Allison	Gary Girdaukas	Don & Hazel Morgan
LAURA BAKER SCHOOL Bruce Jensen	Louise Guido	Bob & Pat Nelson
BAYFIELD Co. DEPT- OF COMMUNITY PROGRAMS Michele Ochsner	Gene & Virginia Johnson	ODTC Debbie Frisk
Mr. & Mrs. Laverne Becker	Bonnie & Tom Jones	ODTC Mark Hohenwald
Lorraine Beirl	Yvonne Jones	Outagamie County DH Gail Hickey
Anne Bresnahan	Donna Kieffer	Florian & Catherine Plon
Susan A Brown, R.N., PH.D.	John & Bonnie Kraft	Nick & Wanda Scheidegger
Virginia Cardarella	Richard & Victoria Kral	Tom & Judy Scheidegger
COMMUNITY TIES PROGRAM Paul White	Michael & Katie Kranjac	Hazel Schuster
COMMUNITY TIES PROGRAM Josh Lapin	John & Pat LaBella	B. Schutz
Carol Dern	Michael & Jeanne Langlois	Duane & Emma Spice
Bill & Gloria Doherty	Rick & Patrice Lapp	Richard Stark
DREAMWEAVERS, Inc Jason Johnson	Lee & Shirley Larson	Russell Stuczynski
Don & Barb Dorn	Michael & Mary Lynn Larson	Mrs. Beatrice Sturm
Jim & Judy Dorn	Kristin Lay	SUNSET RIDGE CARE HOME-Shawn Webb
Mr & Mrs Orville Endres	Arlan & Dorothy Lothe	Rosalie Tillman
Family Support and Resource Center	Robin & Jenny Lucas	Dr. Marc Williams Gunderson Clinic

### PWSA of WI 1997 Membership Renewal

**Name:** \_\_\_\_\_

**Address** \_\_\_\_\_

\_\_\_\_\_

1 Year Membership (\$12.00)

I am financially unable to afford the \$12.00 but would like to become a member.

Make Checks payable and mail to: P.W.S.A. of WI  
305 Amanda Way  
Verona, WI 53593

## IS IT TIME TO EAT???

By Jenny Lucas

That is the most often used phrase in our house...how about yours? Our four year old daughter, Angela, is very speech delayed but that is one of the clearest sentences in her vocabulary! It is always a challenge to find good tasting, low calorie, low fat recipes. I myself have always battled a weight problem, so I have dozens and dozens of low calorie, low fat cookbooks, magazines and computer software programs. Although, even the best planned "diet" recipes sometimes are not even low enough in calories and fat for "our kids", so I'd like to share my favorite adaptations with you. Coming in the next newsletter will be a detailed review of the best computer software programs that I've found, but for now, here's a few recipes to sample.

### Seafood and Pasta Frittata

*For the very hearty eater, this is sure to satisfy.*

8 ounces thin spaghetti  
 2 tablespoons + 2 teaspoons reduced calorie tub margarine  
 ½ cup chopped onion  
 ½ cup chopped red or yellow bell pepper  
 ¾ cup shredded zucchini  
 1 ½ cups egg substitute  
 16 ounces flaked crabmeat or imitation crab  
 5 ounces frozen small salad shrimp, thawed  
 3 tablespoons grated Fat Free Parmesan cheese  
 1 cup shredded 50% Reduced Fat Mozzarella cheese

1. Preheat oven to 350 degrees. Spray a 13 x 9" baking pan with non-stick cooking spray.
2. In large saucepan of boiling water, cook spaghetti 9-11 minutes, until tender; drain and rinse with cold water.
3. Meanwhile, in large non-stick skillet, melt margarine; add onion, bell pepper and zucchini. Cook, stirring frequently, 6-8 minutes, until tender; set aside.
4. In large bowl, combine egg substitute and spaghetti. Add vegetable mixture, crabmeat, shrimp, Parmesan and mozzarella cheese; mix well.
5. Pour spaghetti mixture into prepared pan. Cover with foil; bake 25 minutes. Uncover and bake 10 minutes longer, until golden and set. Let stand 5 minutes before cutting into 9 even pieces.

Makes 9 servings. Per serving: 252 calories, 6.5 g fat

### Chicken Enchilada Casserole

*Put a little zing in your dinner plans tonight!*

1 tablespoon walnut oil  
 2 cans (5 ounces each) mixed chicken  
 1 medium onion, chopped  
 1 can (4 ounces) diced mild green chilies

1 package (10 ounces) frozen whole kernel corn, thawed, drained  
 1 jar (16 ounce) mild or medium salsa  
 2 cups shredded low fat Mexican blend Monterey and Colby cheese  
 9 (6-inch) corn tortillas

Toppings (optional and not calculated into recipe):

Fat Free sour cream  
 Additional salsa  
 Chopped onion

Preheat oven to 350 degrees. In medium skillet, saute chicken, onion and chilies in walnut oil until onion is tender. Spray a 13 x 9 baking pan with non-stick cooking spray. Place 3 tortillas in bottom of pan, overlapping to make a solid layer. Spoon ¼ the chicken mixture onto tortillas, pour ¼ package corn over chicken mixture, pour 1/3 of salsa over corn, sprinkle with 1/3 of the cheese. Place 3 more tortillas over top of cheese and repeat the above layering. Then 3 more tortillas on top. Spread remaining salsa over the entire top.

Cover and bake 30 minutes or until heated through. Sprinkle with remaining cheese and bake uncovered an additional 5 minutes. Cut into 9 equal pieces.

Serve with fat free sour cream, additional salsa and/or chopped onions if desired.

Makes 9 Servings. Per serving: 237 calories , 8 grams fat

### Cashew Meringue Cookies

*And, for those who can afford a sweet on a special occasion, here's an amazing little cookie with only 16 calories!*

4 egg whites  
 ½ teaspoon cream of tartar  
 1 cup sugar  
 1/4 cup ground dry roasted cashews

Preheat oven to 250 degrees. Cover cookie sheet with parchment paper. Set aside.

Beat egg whites in large bowl with electric mixer until foamy. Add cream of tartar, beat until soft peaks form. Gradually add sugar, beating until stiff peaks form. Fold in cashews.

Drop teaspoonfuls of egg white mixture onto prepared cookie sheet. Bake 30 minutes or until lightly browned.

Makes 3 dozen cookies. Per cookie: 16 calories, less than 1 g fat

## SPECIAL EDUCATION FOR A CHILD WITH EXCEPTIONAL EDUCATIONAL NEEDS

Pat LaBella

According to Federal law, each state is ordered (mandated) to provide a "free and appropriate education" for every child in that state. No matter what their parent's income, children are entitled to a "free" education, in a public school, with an education program that is "appropriate" for that child's individual academic needs. In most states, the law requires formal education to begin at the age of 5-years. Some states require a child to begin school with kindergarten, other states require school to begin at the first grade level.

However, if you have a young child with special needs, like Prader-Willi Syndrome, he/she may need a head start in school. Your child's education program may begin with a "Birth to 3 year old/Early Childhood or Early Intervention Program" with services provided by your county. Or, your child may need the services of a "3 to 5 year old/Early Childhood Program" with services provided by the school district in your city. Counties are required to provide early intervention services for children from birth to 3 years old. Local school districts are not required to provide "Birth to 3 year" services, but they are required to provide "3 year to 5 year/Early Childhood Programs

At this point you may have a lot of questions: "Is my child eligible for services? If so, how do I access services for my child? Do I call the county, the school?" I would suggest starting with a call to your neighborhood school. Explain your situation to the school secretary and ask him/her to point you in the right direction.

### REQUEST FOR "M-TEAM" EVALUATION

Once you have located the appropriate contact person at the county level or local school district level, write them a letter requesting that your child be given an "M-Team Evaluation". Be specific about reasons why you think your child has some "exceptional educational needs". (Ex: He is two years old and he does not walk. Or, she is four years old and she has limited speech.) Date the letter, make a copy of it for your files and send the original to your contact person in the education system. This is your formal request for evaluation and services.

### THE "M-TEAM"

Upon receipt of your letter, the education system is mandated by law to respond to your request for an M-Team evaluation. In order for the education system to determine whether your child is eligible for services, a group of people (the M-Team) must evaluate your child. "M-team" means multi-disciplinary team. The M-Team consists of the parents and several educators with specialties in a variety of areas. For example: an Early Childhood teacher; a Speech and Language Therapist; an

Occupational Therapist; a Physical Therapist; a Nurse; etc.. These professionals will do individual observations and evaluations of your child. Then, each specialist will write a report summarizing their evaluations. Each M-Team member will share his/her findings with the whole M-Team at a pre-scheduled "M-Team Findings" meeting. Remember, the parents are important members of this M-Team.

After hearing the reports from each specialist the M-Team members will decide if the child needs special education services. If your child needs services, the M-Team will define which specific services are needed. If your child is declared a child with "Exceptional Educational Needs" (EEN), this M-Team process (evaluations and reports) is repeated every three years.

### INDIVIDUAL FAMILY SERVICE PLAN (IFSP) or INDIVIDUAL EDUCATION PLAN (IEP)

If your child needs special education services, an Individual Family Service Plan (IFSP) or an Individual Education Plan (IEP) must be developed every year. An "IFSP" is a document which outlines annual functional goals and objectives for a child who is in the birth to 3 year old age range. An "IEP" is a document which outlines functional and academic annual goals and objectives for a child in the 3 to 5 year old range. The IFSP or IEP committee consists of the parents, the Special Education teacher, and staff from the related services (ex. Occupational Therapy, Physical Therapy, Nursing, Speech and Language Therapist etc.). The IFSP or IEP Committee works together to write an IFSP or IEP which will meet your child's individual functional or educational needs.

### PLACEMENT

The Placement committee is a group of people, at the school administrative level, who decide which program your child will be placed in. Parents are not usually members of the placement committee. The placement committee will inform the parents of the location where your child will receive his/her educational services. Depending on the results of the M-Team evaluations, your child may be placed in a specific category. For example the term: "L.D." means Learning Disability; "E.D." means Emotional Disability; "C. D." means Cognitive Disability (this replaces the old term mentally retarded); "OHI" means Other Health Impaired. OHI means that while your child may not meet the qualifications for other categories like L.D., E.D., or C.D., he/she does have a health related disability which qualifies him/her for exceptional educational services.

(Continued on page 7 See **IEP**)

**IEP** (Cont. from page 6)

Federal law mandates that within a 90 day time period, the education system must do the M-Team evaluation and if needed, create an IFP/IEP and place your child in a "free and appropriate" education program. The 90 day timeline begins when the education system receives your written request for an M-Team evaluation.

If you need further explanation about any of the above information, call you local school and ask to speak to the principal or a school counselor. They will be able to help you.

*Submitted by Pat LaBella, B.S.Ed., Secretary of PWSA of WI. Teacher, mother of 4 children. Pat's 17 year old daughter has Prader-Willi Syndrome.*

**Contributions and Thanks**

United Way of Greater Milwaukee  
 United Way of Brown County (Mary Lynn Larson)  
 Dorothy and Arlan Lothe  
 United Way of Greater Milwaukee (Sharon Zagorski)  
 United Way of Greater Milwaukee (Richard Becker,  
 Tom Grail, Mary Mankowski)  
 Duane and Emma Spice

**Conference Update**

Prader-Willi Syndrome Association of Wisconsin and RFDF Community Living. are planning another PRADER-WILLI SYNDROME TRAINING DAY.

When: Friday October 10, 1997.

Where: Madison Area (location to be determined)

This day long training seminar will include large forum and breakout sessions. This training is open to anyone with an interest in PWS and no past experience is required. Look for more information in the August issue of The Wisconsin Connection.

**PWSA (USA) National Conference Registration**

The cutoff for registration for the National Conference is quickly approaching. If you plan on attending the conference your registration must be into the national office by June 20, 1997. Please sign up early. This year the conference is being held July 15-18 in Orlando, Florida.

It promises to be another outstanding conference. If you have any questions about the conference please call the state or national office.

**Imagine** (Cont. from page 3)**HOW CAN YOU HELP?**

If you know someone who has Prader-Willi Syndrome, you can refer them to the national organization or local chapter. You can offer non-judgmental support and a listening ear to the families and caregivers, understanding that it is very stressful to cope with PWS.

You can educate yourself by subscribing to publications of the national and local organizations.

You can volunteer to help with chapter activities, such as the annual PWS Awareness Day event.

You can make a financial contribution to the chapter, which endeavors to offer support and information to the families and to educate the community about Prader-Willi Syndrome through the distribution of brochures and through publishing a quarterly newsletter "The Wisconsin Connection." These projects are supported entirely by individual contributions. PWSA of WI is a non-profit organization incorporated in the State of Wisconsin, and as such, your contribution is tax deductible. Make checks payable to PWSA of WI and mail to the state office.

**Did You Know?**

Did you know that you can chat live online with other parents and persons interested in PWS. If you have access to the Internet go the PWSA (USA) web page ([http://www.athenet.net/~pwsa\\_usa/index.html](http://www.athenet.net/~pwsa_usa/index.html)) and enter the chat area. You can also find parents of individuals with PWS who are interested in contacting other parents through email at the same web site.

These web pages have been accessed by over 8000 people in the past 10 1/2 months. There are links to the web pages from many different countries and prominent medical facilities, including John Hopkins, Mayo Clinic, American Medical Association and the new government health super web site. There have even been diagnosis's made from information learned from the nationals web pages.

Several other state chapters have web pages including the Wisconsin chapter.. Once at the national web site there are links to many other sources for information about PWS.

If you have any recommendations for online resources from PWSA (USA) just contact the national office at [pwsausa@aol.com](mailto:pwsausa@aol.com) or [pwsa\\_usa@athenet.net](mailto:pwsa_usa@athenet.net). You can even use the old fashion way of snail mail or telephone. So, if you want to meet others who live with or are interested in PWS hop on the Net and surf.

MARK YOUR CALANDER  
AUGUST 23, 1997

# PWSA of WI SUMMER PICNIC

Look for more details soon!

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