

## The first anniversary

By Jane Ore

There is a nagging within me that will not go away. It is my introspective self that wishes to come forth and share something deep and personal with you. But it also is shy. The introspective self does not want to impose on you, but rather share with you a story about personal conflict and triumph. I hope that in the sharing of experiences some good will come of it. So, with deep respect to all who read this I'd like to share my feelings and thoughts with you about the first anniversary of my son John's death.

The first anniversary as "they" say, is the worst. But, what "they" neglected to inform us of is that it also can be liberating. Have you ever had one of those watershed moments when something profound hugs your inner being and from that moment forth (because it is a growing in understanding life) you are comforted and enlightened by its revelation? A moment so clearly felt that you actually feel lighter? I had one of those moments on the anniversary of John's death. And it was liberating.

I'm a creature who enjoys and needs rituals. I am comforted by the fact that these rituals are a sign of respect and love. As my son's first anniversary was approaching, I started to become apprehensive. I did not know how to ritualize his passing in a way that would celebrate life and not center on my loss.

I decided not to decide. I had a few things that I knew I needed to do. One of these was to take the day off. Another was to have my other two children with me. And I knew I wanted to let balloons go at his gravesite. With these few "need tos" I felt that the rest would fall into place. I was trying not to have too many expectations on that day.

Because that day was to be bad to begin with, I didn't want to make it worse. Yet, somehow my apprehension grew. Something was not quite

right. I wanted to remember my John. I even wanted to feel that intense sorrow, because it made me feel closer to him. I just didn't want to forget. But time moves forward. Memories go from vivid colors to sun faded shades to soft pastels. And I wanted to stop that. Even the favorite outfit of his that I had saved was beginning to smell dusty. DUSTY!

Time was an enemy taking my beloved memories and softening them. I didn't want time to heal my wounds. I wasn't ready. But of course, time will not wait for us to catch up. And I am very stubborn. I remember hearing a song on the radio that asks, "Why do you lock yourself up in these chains? You have no one to blame for your unhappiness." My head knew that I needed to move forward, but my heart still was in fragmented pieces. My heart just didn't know how to go forward without losing touch with my Johnny. My heart didn't know how to let go!

So the day brazenly arrived, almost as if it were daring me to see it through to tomorrow. The kids and I went to church that morning and met my mother there. After Mass, we went out for breakfast. I felt as if I was being pulled. I didn't want to be there, yet I didn't not want to be there. I was very aware of life around me and how I felt out of place. My John died around 10:30 in the morning, so I was very conscious of the time. After breakfast, my mother suggested we go to a dime store and look around. Even though I was not in a looking mood, I thought Becky and Bobby (my other two children) would enjoy it.

Well, this was one of those dime stores that is full of life. Items to touch, pick up, try on, ponder, etc. The kids were all over the place. "Mommy come and see this." "Mommy can I have only just one?" "Please Mommy, just one."

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As I went from one to the other looking at the treasures they found and telling them “not today,” I lost track of time.

The next time I looked at my watch it was 11:30 a.m. The moment had come and gone. The kids were happy with their loot. My mother’s feet were starting to hurt. And I was OK. Life continues despite the pain and sorrow. Moments are meant to be just that: moments. Whether they are moments of joy or sorrow, they do not last forever, and that can be good.

We went home after that. My mother dropped us off. But the day was not over. I still needed to visit the gravesite and let some balloons go. So the kids and I went to the store, bought our balloons and journeyed to the cemetery. They liked letting the balloons go too, so it was a ritual we all participated in.

We did our thing, wrote messages on the balloons and one by one, we let each balloon go. We each said something as we let them go. We each took a turn. And we watched each one as it floated up and out of our sight before the next one went. It was a reverent moment. We were remembering. We were sad.

And then, Bobby and Becky started to jump over the gravestones. They started to chase each other. They were enjoying life.

I was just standing there by myself, thinking to myself, crying to myself. I watched the two of them running around and was grateful that they were enjoying themselves. After a time, we started to walk back to the car. The two of them were racing to see who could reach the car first. I kissed two fingers on my hand and bent down to touch the kissed fin-

gers to John’s grave. I slowly started to walk to the car. And the most amazing thing happened.

I started to smile. My head felt as if it were in tune with my heart. I finally understood what my heart knew all along. My heart didn’t know how to let go, for it would never let go. What I needed to learn was how to live with my Johnny after his death and not to try and live without him.

Death is centered on loss. Maybe it should be centered on the living and how we live with our loved ones who have died. This revelation has had the most profound effect on me. I remember walking away from John’s grave and thinking that this is what I will do next year. It felt so right. The kids and I had created our own ritual. It was a comfort to know that next year was already planned in a way; that my Johnny would not be forgotten and that we would do our thing. And yes, life will go on. For life always does, whether we are willing to go on ourselves or not.

It is not always easy to accept that fact. Some of us may reach that understanding earlier in the process; others of us later. But it is my hope that we all feel that moment when understanding and a sense of calm flood our beings and comfort us. I believe when that happens we become even closer to our dear, beloved children who have died; gone on ahead to wait for us. We no longer fight the truth of their deaths. But we take it into our very being and make it a part of who we are. I believe my life is richer because of John. He has given me many gifts, of which there are still many to be opened.

Here’s to the growing, the understanding, and the many gifts that are left for all of us to open and discover. ❖

## The Spring Family Bereavement Conference, “Stepping Stones”

April 22 (7-9 p.m. registration); April 23 (8 a.m.-3:30 p.m.); Wisconsin Dells, Wis.

Keynote Speaker: Deb Smith-Jones, bereaved parent

The conference is intended to help families develop the skills to integrate the death of their infant into their life. A number of alternatives are available to assist individuals and families in networking and developing their coping skills. We encourage you to take breaks and time for yourself to think, release stress or just relax.

Ralph Franciosi, M.D., our medical advisor, will be available to meet with families on an appointment basis to discuss questions and concerns. If interested, call the central office at (414) 266-2743 for an appointment and/or further information.

Cost: Adults \$15 each, includes continental breakfast, lunch and conference. Children \$5 each, includes materials and child care. A mailing will be sent out. Call for more information. If you have not received an invitation, please use this form to begin the registration process. This conference is partially funded by a grant from the CJ Foundation.

Name \_\_\_\_\_

Address \_\_\_\_\_

Number of adults attending \_\_\_\_\_ Number of children attending \_\_\_\_\_ I will be using child care \_\_\_\_\_ Yes \_\_\_\_\_ No \_\_\_\_\_

## Avoid cough suppressants

By Ralph A. Franciosi, MD – *Franciosi is program director of Perinatal and Infant Pathology at Children's Hospital of Wisconsin and a professor of Pathology and Laboratory Medicine at the Medical College of Wisconsin.*

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A Sudden Infant Death Syndrome (SIDS) death relates to a combination of three factors: a vulnerable infant, a critical developmental period after birth and environmental triggers and stressors. Our research efforts are directed toward understanding what makes an infant vulnerable and defining the critical developmental period after birth. These studies are very complex and will take years to complete. Meanwhile, we encourage a practical approach for reducing risk factors associated with SIDS. One potential risk factor is the use of cough suppressants.

In 1985, A. Kahn, MD, and his colleagues at University Hospital in Belgium, wrote an article about the adverse effects of medications containing phenothiazine on infants. The arti-

cle stated a therapeutic dose could change an infant's sleep characteristics and result in central, obstructive apnea. They recommended central nervous system depressants be avoided in infants under one year of age. The Committee on Drugs of the American Academy of Pediatrics recommended drugs used to suppress a cough be avoided in children, especially infants. Their statement noted that numerous over-the-counter cough and cold medications are available and most cough suppressants contain a mixture of dextro-methorphan or codeine, antihistamine, decongestant and expectorant in elixirs that contain alcohol. The dextro-methorphan and codeine are thought to act directly on the central control of coughing in the brain stem

and have the same potential to affect infants' sleep characteristics as central nervous system depressants.

To avoid potential risks, suppressant cough remedies for infants are discouraged. In addition, the Back to Sleep campaign also attempts to reduce risk factors such as prone sleeping and sleeping on a soft surface. Other known risk factors are maternal smoking and infant exposure to second-hand smoke. Because these risk factors seem to increase the incidence of SIDS, parents are encouraged to protect their infants from exposure to the effects of smoking, both before and after birth.

To help avoid potential risks to infants, we will continue to update you on risk factors. Your physician also is a valuable resource. ❖

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## Twenty-five years of service: A history of the Infant Death Center of Wisconsin

This year the Infant Death Center of Wisconsin (IDCW) begins its 25th year serving the families of Wisconsin. The IDCW began as a program dedicated to serving families impacted by Sudden Infant Death Syndrome (SIDS), while doing research to find the cause of unexplained infant death. The program began at the Medical College of Wisconsin and has been at Children's Hospital of Wisconsin since the late 1980s. In the beginning, the IDCW was funded under the SIDS Act of 1974, and eventually it became funded through the federal government's block grant programs. The block grant programs allowed individual states to develop goals and use the federal funding to meet those goals. Throughout the last 25 years, the program has received significant funding from Children's Hospital of Wisconsin, grants, private fundraising and from individual donors. Without these funding sources, we would not have the program we have today.

The services provided to parents by the IDCW include:

family contact, bereavement support, home visits by local public health nurses, support group meetings, the annual family conference, memorial programs, peer parent support, consultation with our medical advisor, a Web site ([www.idcw.org](http://www.idcw.org)) and the *Wisconsin Perspectives* newsletter.

The IDCW also provides educational services to the community and to professionals. These include information on: reducing the risk of sudden and unexpected infant death, supporting newly bereaved families and the latest research around sudden infant deaths. This information is provided through training programs across the state, consultation, written information, and service on a variety of committees and work groups.

The role of education and prevention has taken a greater meaning as more is learned about SIDS. Infant deaths have many complex factors. We realize the power of education in

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empowering parents to ensure the best chance for their child's health and safety, and we have aggressively sought to bring information to families around the state. We partner with many groups to identify trends in infant deaths and to bring timely information to families and health care providers. Our joint efforts allow us to use the resources available as efficiently and effectively as possible.

We know that the coming years will have new challenges, but we hope to build from our past experience and continue to work toward the day when fewer families have to endure the pain of the death of an infant.

We appreciate the trust that families and funders have given us. That trust allows us to support families at the most painful time of their lives, to educate our communities, and to collaborate toward healthy infants and families. We thank those whose support has made this possible, and we look forward to serving you in future years.

### *A summary of the IDCW's impact on families*

The IDCW has accomplished a lot in 25 years of service to the residents of Wisconsin. Listed below are the needs the IDCW addressed throughout the last 25 years. The Center hopes to continue addressing these needs, and other new ones as they arise, in the years to come.

#### High rate of deaths due to SIDS

Researchers identified a syndrome in which infants were dying and there was no apparent cause for the death. In Wisconsin, the rate in 1980 was 1.54 for every 1,000 births. The rate increased in 1985 to 1.955 and in 1990 it was 1.57.

#### *Key accomplishments by the IDCW:*

- Aggressive marketing of the Back to Sleep Program across the state may have contributed to Wisconsin's SIDS death rate to drop to 0.486 in 2003 from the high in 1985 of 1.955.
- Involvement in collaborations with key strategic partners to bring information on strategies to reduce the risk of sudden and unexpected infant deaths to the general public, with special emphasis on high-risk communities.

#### Need to support all families who sustain a sudden infant death regardless of the cause

Families whose infant had died suddenly and unexpectedly had no system of support to assist them in their grief. In addition, there was no systematic way for public health to address the problem of sudden deaths and work toward understanding the problem and identifying strategies to reduce the number of infants dying.

#### *Key accomplishments of the IDCW:*

- State of Wisconsin and Children's Hospital partner to expand program beyond an emphasis on SIDS.
- Outreach to coroners and medical examiners to ensure timely receipt of referrals and make sure families receive bereavement support early in their grief.
- Focus groups to identify how the program can better serve all families referred.
- Periodic family satisfaction surveys to identify issues of concern.
- Development and refinement of a questionnaire for parents to assist in understanding and identifying the factors and common elements involved in the infant's life and death.
- Provide bereavement support through telephone counseling (served more than 330 families in 2004).

#### Racial and ethnic disparities in infant mortality

Wisconsin's ranking among states in infant mortality has declined. For the period of 1979 to 1981, Wisconsin ranked fifth among states for white infant deaths, and fourth for black infant deaths. For the period of 1999 to 2001, the ranking fell to 27th for white infant deaths and to 32nd for black infant deaths.

#### *Key accomplishments of the IDCW:*

- Developed and provided outreach worker training programs statewide to engage home visitors to bring risk reduction information to families.
- With Milwaukee Fetal Infant Mortality Review Program and hospital nursing executives, developed a hospital collaborative to change practice patterns in Milwaukee area hospitals to ensure consistent practice and education in the City of Milwaukee.
- Developed and disseminated a Public Service Announcement in Hmong for radio on reducing the risk of SIDS.
- Functioned as lead agency in planning and execution of Healthy Babies in Wisconsin Perinatal Summit, which provided new information on addressing infant mortality to health care professionals on Perinatal Periods of Risk and the Life Course Perspective.
- Assisted in implementation of regional action teams following summit.
- Provided outreach to high-risk populations to disseminate risk reduction message.
- Collaborated with community agencies to provide social marketing to reduce sudden and unexpected infant deaths.
- Involved in infant mortality studies with a goal of reducing infant deaths.

#### Professionals need for information on dealing with grieving families

Professionals found themselves dealing with situations for

which they were unprepared and in need of training and support to address and meet the needs of the public they serve. In many parts of the state the incidence of infant death is relatively low, and therefore support and training for professionals is minimal. Over time the ability to travel for such education has decreased due to budget constraints.

#### *Key accomplishments of the IDCW:*

- Developed “What Families Tell Us” video.
- Ralph Franciosi, M.D., medical advisor, authored book “Understanding Crib Death,” which was distributed to families and professionals.
- Developed and disseminated emergency room guidelines in handling sudden and unexpected infant deaths.
- Held annual professional conferences, which moved to regional training programs to accommodate changing regional needs.
- Provided medical consultation.
- Collaborated with Northeast Wisconsin Technical College to provide training programs.
- Developed Public Health nurse manual and disseminated to assist in supporting families.
- Held statewide public health nurse trainings.
- Medical advisor and staff available for consultation to physicians, nurses, counselors, coroners, medical examiners, law enforcement and others dealing with infant deaths.

#### **Regional needs of the state**

Family needs vary by geographic region. Issues of population density come into play in determining needs and services.

#### *Key accomplishments of the IDCW:*

- Regional satellite offices provide services to communities throughout Wisconsin.
- Regional community councils engage key stakeholders from the area to address specific regional needs and provide advice and counsel to ensure effective programming is in place.

#### **Research needed to identify causes of SIDS**

Both families and professionals dealing with infant deaths have many medical questions related to the cause of death and research results and recommendations that are published. Autopsy results can be difficult to interpret and leave many questions for both parents and professionals. The information and recommendations from research can be confusing and at times contradictory. The need for guidance from a pediatric pathologist is clear.

#### *Key accomplishments of the IDCW:*

- Physician was brought to the program to provide medical direction and participate in research leading to the reduction in SIDS deaths in Wisconsin.
- Researchers at Children’s Hospital are in collaboration with other national researchers to identify factors involved in a SIDS death.
- Program worked with Association of SIDS and Infant

Mortality Program Professionals to develop a tool to assist in identifying common factors related to SIDS.

- Involved in planning and participated in invitational meeting to address the issue of infant deaths.
- Medical advisor authors a research update published in *Wisconsin Perspectives*.
- Medical advisor available to interpret research information released to the public.
- Medical advisor presents at international conference on SIDS.

#### **SIDS deaths in child care**

National research indicated 20 percent of all SIDS deaths occurred while infants were in child care. Wisconsin statistics reflected similar numbers. Upon further study it was determined that many child care providers were unaware of the strategies they could use while caring for infants.

#### *Key accomplishments of the IDCW:*

- Developed curriculum and provides statewide training of child care providers.
- Developed curriculum for “train the trainer” programming and provided statewide.
- Provided consultation to child care providers on issues related to sudden and unexpected infant deaths.
- Collaborated with Northeast Wisconsin Technical College in the development of an online training program to meet the state requirements for certification or licensure.

#### **Declining financial support**

Funding changed from dedicated federal funding to block grant funding through the state, competing with multiple public health goals and needs. Over time funding has decreased substantially leading to a greater dependence on grants and donations to maintain programming.

#### *Key accomplishments of the IDCW:*

- Secured grants through the Department of Health and Family Services, the CJ Foundation and the March of Dimes to fund center operations.
- Through the support of Children’s Hospital and Health System Foundation, developed support for families who wish to fundraise for the IDCW in memory of their child.
- Worked with Children’s Hospital and Health System Foundation to provide families an opportunity to target donations to an endowed fund (permanent) in their child’s memory over a five-year period.
- Children’s Hospital and Health System support combined with contributed dollars account for over \$125,000 per year to support the IDCW operations. ❖

## Intensity of grief will fade; intensity of love will not

By Mary Miskulin-Sjojren

Our first child, Rebecca Mari died of SIDS on December 28, 1995. She was three months old. There was a lot of discussion about grief after she died – from family, friends, the support group. I have come to realize that we continue to grieve long after the death of a loved one. It is not as conscious as it once was, not as immediate. But it is there all the same, and will be until we ourselves are gone.

After Rebecca died, a question came into my mind that nagged at me for the longest time. If the intensity of the pain recedes over time, does the intensity of the love I feel for my daughter also fade? Not the love itself, but the intensity of the love. It may sound like the same thing to some people, but to me there was a difference. No one could give me an answer, not even other moms whose babies had died and were farther down the road of grief than I was. It bothered me to think that maybe it was true.

I kept a journal after Rebecca died and still write in it, although not as frequently. As you can see from the excerpt below the date is almost six years after Rebecca died. On that day I finally got my answer. It was like an epiphany. I had answered my own question.

Wednesday, December 12, 2001

*I was at work this morning, and my thoughts got to wandering. I thought about the world-wide candle lighting that happens the second Sunday in December, and was just December 9. I sent the information to everyone in our e-mail address book so that as many people would get it and pass it on. After I gave all the details, I said that it was in memory of all the little ones who died before we were ready to give them up. And today when my thoughts were all over, I thought about the cemetery and lighting candles there. And then for some reason I thought about the*

*emergency room and what happened that day. Some images are still so clear, and I started to cry at work. We didn't want to give you up. We just kept holding you, missing you, crying for you. And we felt so empty when they took you away. Giving you up was the hardest thing I've ever done.*

*And now it hurts so badly. I realize that your anniversary is coming up, and can't believe so much time has gone by. And I can't believe the intensity of the pain I am feeling right now. Yes, I can. I know that I wouldn't be feeling like this now if I hadn't loved you so much. And although I don't feel this pain as often as I did when you first died, it doesn't mean that intensity of our love has diminished at all. It is as strong as it always was. But perhaps I needed to be reminded, because I sometimes feel that I don't think of you as often as I should, and feel guilty for that. We get caught up in the everyday details of our lives, and forget to stop and realize what is important. And yet I do think of you. I see the baby's breath on the sill in the kitchen, and it is there for you. I see the little girl statue that Lori gave me, and it is there for you. Your ring is on my necklace. Your picture is at work. But I also took your picture off the corner table recently, and realized that I hadn't looked at it – really looked at it – for quite a long time.*

*But you are in my heart. You always will be. You were our first baby, the one who made us realize how much love we had to give a little one. You made us less selfish, more giving. You made me feel so content. I think about the times in the apartment when I gave you a feeding in the middle of the night, and then we'd fall asleep on the couch together, with you in the crook of my arm. You were so tiny. You fit there so well. We were so blessed to have you, even for the little time we did. I hope*

*you know how much we love you, and how much we miss you.*

And so my conclusion is this: the intensity of the love will always be as strong as the day Rebecca died. The pain that I felt the day I wrote the journal entry is a testament to that. I finally understood that we just cannot live our daily lives with the intensity of the pain. And so we move on in our journey of grief, at some point maybe even thinking that we are healed. But then a day comes along when the wound is opened, and we feel again the loss and longing for our child. At that moment we experience the intensity of our love for our child, and know that nothing will ever take that away. ❖



# Gifts

The Infant Death Center of Wisconsin thanks the following individuals for their generous donations in honor of someone or in memory of a special child.

These donations were received between Oct. 1, 2004 and Jan. 31, 2005

## In memory of:

### Alex Amundson

Dick and Peggy Larsen

### Erik Baumler

Mr. and Mrs. Richard Baumler

### Christopher William Beno

Mr. and Mrs. Mark T. Beno

### Julianna Chole

Mr. and Mrs. Bruce L. Schneider

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### Ann Mortenson

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### Chavala Madeline Pilmaier

Mr. Andrew J. Nordin and Ms. Lisa Marie Bergh  
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Mr. and Mrs. John L. Strobel

### Madeline R. Thorpe

Mr. and Mrs. Daniel N. Burnside

### Cassidy Tiana Weyek

Mr. and Mrs. James A. Weyek

## In honor of:

### Mason Riley and Carter Ried

Mr. and Mrs. Bruce L. Schneider

## To make a gift

Children's Hospital and Health System Foundation is available to assist you if you or your organization is interested in making a donation to the Infant Death Center of Wisconsin (IDCW) in memory of a child or other person. Annual giving and memorials are handled through the foundation and recognition opportunities are available. To reach the foundation office, call (414) 266-6100.

Periodically throughout the year, you may receive mailings from the foundation seeking support. Often there is a card enclosed with options for giving. Please feel free to check the IDCW as an option, or write in the center if it is not listed on the card.

The center also can be chosen as an option on your United Way designation form, however, it must be written in. Your support of the program allows us to provide a continuum of services throughout the state. Please know this support is most appreciated.

Many companies provide a match to donations given by their employees. You may wish to check with your employer to see if such a program is available to you.

*Wisconsin Perspectives* is the newsletter of the Infant Death Center of Wisconsin. The goal of this newsletter is to promote the statewide exchange of information regarding infant death issues.

The Infant Death Center of Wisconsin is funded by Children's Hospital of Wisconsin and a MCH Title V Services Block Grant, through the Maternal Child Health Bureau of the Health Resources and Services Administration, Department of Health and Human Services.

If you are receiving this newsletter for the first time, it is because you have been referred to the center at Children's Hospital of Wisconsin. Please contact us at (414) 266-2743 if you wish to be removed from the mailing list. Contact Anne Harvieux, program administrator, at (414) 266-2746 or [aharvieux@chw.org](mailto:aharvieux@chw.org) with any questions or comments about the program or newsletter.

To reach the center and the South/Southeastern regional office, contact Anne Harvieux at (414) 266-2746 or [aharvieux@chw.org](mailto:aharvieux@chw.org), or Larry Uglow at (414) 266-2745 or [luglow@chw.org](mailto:luglow@chw.org). To reach the satellite center in your region, contact Dora Gorski in Northern/Western Wisconsin at (715) 843-1877 or [Dora.gorski@cssw.org](mailto:Dora.gorski@cssw.org), or Beth Tourville in Northeastern Wisconsin at (920) 969-7903 or [Btourville@chw.org](mailto:Btourville@chw.org).

## New arrivals:

Congratulations to the following families or their new additions:

**Jaylen E. Hooker** was born Aug. 3, 2004, to Marqueesha Riley and Talvary Hooker.



**Grace Teresa Rasch** was born Sept. 12, 2004, to Michelle Twardy and Ryan Rasch.

**Colman Samuel McGuire** was born Sept. 16, 2004, to Thersea and Michael McGuire.

**Reagan and Logan Wilson** were born Oct. 18, 2004, to Jenny and Jason Wilson.

**Nickolas Gregory Johnston** was born Nov. 9, 2004, to Tanya and Greg Johnston.



**Precious Lynee Oliver** was born Nov. 18, 2004, to Nanette Oliver and Laterrance Carr.

**Regan Noelle Staudt** was born Dec. 22, 2004, to Lisa and Brad Staudt.

If you would like your baby's name added to this list, call your regional office:

South/Southeastern (414) 266-2746

Northern/Western (715) 843-1877

Northeastern (920) 969-7903



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