

Will it ever be spring?

By Darcie D. Sims

Do you ever wonder if it is ever going to end? The calendar says it is spring now, and still IT remains. The days are growing longer; the dawn arrives a little earlier and the twilight lingers a few extra minutes each week. The air moves in a breeze instead of a winter gale, but IT remains. There are definite signs of a warming trend on the television weather map, and I thought I saw a tender bud beginning to rise on one of the bushes. Some of the sounds of spring are beginning to return to a land that has remained frozen and barren for so long – and yet, IT remains.

The arrival of a gentler season is proclaimed by catalogs that stuff the mailbox on a daily basis. But, IT remains. The calendar says that Easter is late this year. Is that because the Easter Bunny is getting older and therefore, a bit slower in his old age? The calendar also says that two months already have been spent out of the new year and time's a'wastin'.

According to the fashion magazines and the store displays, we all missed spring last winter. Why are they always a season ahead? Who wants to think about bikinis when one is bundled in sweaters three layers deep? Is the entire world out of sync or just me?

Spring seems far away right now. There isn't much lightness to my step or my heart, and I figure my tulip bulbs got put in upside down anyway. (Is someone in China enjoying my emerging bulbs?) The ground still is frozen up here in the far north country, and the only thing peeking out of the ground is more snow. Now I know why Easter eggs are colored – it's the only way the kids can locate them in the snowdrifts. Never mind new Easter shoes or a new bonnet, we're still wearing parkas and snow boots.

The traditional Easter Parade really is a march of the snow plows. Yes, the calendar may say spring is coming, but IT remains and I am

beginning to wonder when IT will go away. IT, of course, means snow; but it also means the chill of grief that continues to reside in the heart and in the memory.

We keep hoping that, someday, IT will disappear. The natives tell me that June is nice up here, and we keep waiting for the ice to melt. We also keep waiting for the sadness to leave, perhaps just fading away one night as we sleep. But, grief, like snow and ice, doesn't simply melt away.

We thaw a bit and then an icy wind blows back a painful memory, and winter returns. A warm breeze signals a return of gentler times, only to be blasted away by a whiff of perfume, the snatch of a song, a fleeting glimpse of a familiar face. It can be years later and still we get caught by a moment's memory and the icy winds of winter dash back in to take up residence.

We sprinkle salt on the ice, hoping it will keep the sidewalks clear, but then it melts and puddles, only to refreeze as soon as darkness sweeps across the daylight. Grief is that way, too. We think we are beginning to thaw, only to be reminded, again and again, of our losses.

The beginning of spring causes most of the world to celebrate, but sometimes, IT is too loud for us to hear the robin's first spring song. We keep hoping for the magic that will erase the hurt and melt the ice that remains at the core of our being. We keep hoping for a good weather report so we can plant the spring crops and feel the sun warming the earth. We keep hoping for the good feelings to return. We keep waiting for the us we knew to come back – for the night to disappear and the nightmare to end.

Waiting and hoping won't make IT fade away. Waiting and hoping are passive pursuits –

continued on Page 7

in this EDITION

Personal viewpoint

Pages 1 & 7

Research review

Page 3

Center and satellite summaries

Pages 4 & 5

Memorials/gifts

Pages 6 & 7

New arrivals

Page 8

Visit our Web site at
www.idcw.org

The family bereavement conference: a parent's perspective

By Karen Bullock

For one tragic reason or another, most of us are receiving this newsletter because we unwillingly joined the fraternity of bereaved parents. My husband and I have lost three daughters. It is hard to believe that we have been through so much. One of the things that has kept me going is having the opportunity to get to know and visit with other parents who have lost children.

We went to our first family bereavement conference in March 2004. My husband didn't want to go at first, but he was glad he went. It was held at a water park in Wisconsin Dells. I didn't know what to expect, but figured at the least we would have a good time at the water park. At that first conference, I was able to meet other families who have been through what we have. There was a guest speaker, a memorial service and some discussion sessions. That day, I experienced a variety of emotions. Some parts were hard, but I thought the guest speaker was interest-

ing and found myself on common ground with the other people in the breakout sessions. The environment allowed people to express any emotion ranging from sadness to joy.

I became involved in the planning committee for the conference last year and attended my second conference in April 2005. This was a great opportunity to meet with some families we had met before as well as make new friends. We also met others who had experienced multiple losses. Despite the time that has passed since our first loss on Christmas Day 2002, it always is nice to be in the company of people who are on the same journey as we are. There were people whose losses were recent and some whose losses had occurred years ago. There is no right path through grief, but we meet a lot of nice people on the way. It really helped us get grounded, knowing that we were in the realm of "normal" and that our emotions are OK. It helps to talk with others about issues we all

have in common.

This year, another great conference is coming. *Lighting the Way* will be held Friday – Saturday, April 7-8, at the Wintergreen Resort and Conference Center in Wisconsin Dells. We are looking forward to hearing guest speaker Olon Lindemood and putting together some new breakout sessions along with some of the perennial favorites, such as the Men Only Session. Like past years, there will be a meet and greet session on Friday night with craft time. On Saturday, a memory table will be available for families to display scrapbooks or other things they would like to share.

Regardless of our beliefs, the color of our skin or our economic status, grief puts us all on common ground. One of the greatest things we can do for ourselves and for others is to help each other along this journey. This is a great chance to do just that. ❖

Lighting the Way

The Spring Bereavement Conference, *Lighting the Way*, will be held Friday – Saturday, April 7-8, at the Wintergreen Resort and Conference Center in Wisconsin Dells, Wis.

A committee of parents from throughout Wisconsin is planning the conference. Features of this year's conference include:

- A keynote presentation by Olon Lindemood. Lindemood is the senior pastor at Loveland First United Methodist Church in Loveland, Colo. He has been a presenter for the Colorado Sudden Infant Death Syndrome (SIDS) Program at three parent conferences and comes recommended from conference evaluations.
- An opportunity to meet other families who are dealing with similar situations.
- A program for adolescents (ages 10 and older) designed to allow them to share their grief if they choose.
- A memorial program.
- Breakout sessions.
- An opportunity to take quiet time to reflect, release stress and rejuvenate.
- On-site child care.
- Continental breakfast and lunch on Saturday, April 8.
- Reduced room rates at the Wintergreen Resort and Conference Center (\$62 per night).

continued on Page 5

Prolonged QT Interval as a cause of Sudden Unexpected Death in Infants

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.*

Syncope and sudden death associated with long QT interval usually occurs in young adults. There usually is a family history of syncopal (fainting) attacks or sudden death. However, cases have been reported in infants with a negative family history suggesting that the mutation was spontaneous (occurred for the first time in this family). Could this explain some cases of Sudden Infant Death Syndrome (SIDS)? The diagnosis of long QT interval is by electrocardiogram (EKG). The use of molecular studies to document long QT-associated gene mutations after death is investigational.

The human heart is a muscular pump that supplies poorly oxygenated blood to the lungs to obtain oxygen and well-oxygenated blood to the body to allow organs to function. The heart has four chambers – two atria collect blood and two ventricles pump blood. The pumping action of the heart is performed by two types of muscles. One type is specialized to transmit electrical impulses (conduction) and the other to squeeze (contract). The heart is a unique organ in that it has a self-starting, recurrent beat. The electrical impulse begins in the atria and spreads to the ventricles,

We can measure the electrical conduction in the heart with an EKG (Figure 1). The P wave represents the contraction of the atria, the QRS waves represent the contraction of the ventricles and the T wave represents a return of the ventricles to the non-contracted state (resting position). The QT interval measures the distance between the beginning of the Q wave to the end of the T wave.

Prolongation of the QT interval can cause a brief loss of consciousness

or sudden death through a rapid beating of the ventricles that leads to the inability of the heart to pump blood. This results in lack of oxygen delivery to the body. The cause of the QT prolongation appears to be an imbalance in autonomic stimulation to the heart. Since the leading research into the cause of SIDS implicates a dysfunction of the autonomic nervous system,

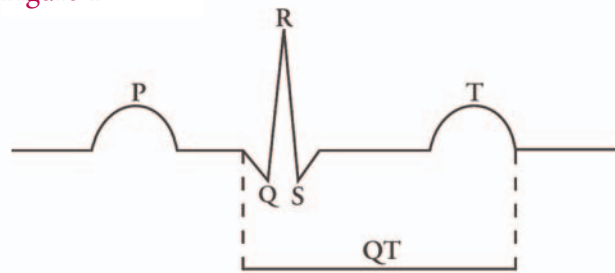
prolonged QT interval has been suggested as a cause of sudden infant death that can mimic SIDS.

In 1998, Schwartz and colleagues reported EKGs finding on 34,442 3- to 4-day-old infants over a 19-year period. Twenty-four of these infants died of SIDS and 12 had significant prolongation of the QT interval.

In 2001, Ackerman studied biopsies of the heart in 93 SIDS cases and detected four infants who died due to long QT syndrome. The genetic form of long QT may account for six to eight percent of sudden infant death cases mimicking SIDS. A striking observation is that one long QT gene mutation causes prolongation of the QT interval during sleep.

In summary, a subset of sudden unexplained infant deaths that mimic SIDS may be caused by long QT syndrome. These deaths would fit the triple risk hypothesis since they occur in a vulnerable infant, during a critical developmental period after birth and are precipitated by stressors and/or triggers such as heat and minor airway obstruction. ❖

Figure 1



or sudden death through a rapid beating of the ventricles that leads to the inability of the heart to pump blood. This results in lack of oxygen delivery to the body. The cause of the QT prolongation appears to be an imbalance in autonomic stimulation to the heart. Since the leading research into the cause of SIDS implicates a dysfunction of the autonomic nervous system,

Center and satellite summaries

U P D A T E

Infant Death Center and South/ Southeastern Region

Anne Harvieux: (414) 266-2746

Vivian Jackson: (414) 266-2745

Educational programs

Oct. 19 - Northeast Wisconsin Technical College - Kickoff of SIDS Curriculum distribution and presentation on SIDS, Green Bay.

Nov. 9 - Milwaukee Healthy Beginnings Project Public Information Committee on Safe Sleep.

Dec. 12 - Northeast Wisconsin Technical College (NWTC), SIDS training for health care professionals, Green Bay.

Jan. 17 - Milwaukee Healthy Beginnings Project Consumer Issues Committee on Safe Sleep.

Jan. 30 - West Allis Health Department inservice on infant mortality and SIDS.

March 4 - African American Infant Mortality Health Fair, Beloit.

Informational exhibits

March 4 - African American Infant Mortality Health Fair, Beloit.

Support to families

April 7-8 - Spring Family Bereavement Conference, Wintergreen Resort and Conference Center, Wisconsin Dells.

May 7 - Spring Memorial Program, Zoofari Conference Center, Milwaukee.

Media interviews

Jan. 17 - *Milwaukee Journal Sentinel* article about safe sleep environment.

Other

Oct. 26 - Meeting with the women in the National Association for the Advancement of Colored People discussing infant mortality, Racine.

Dec. 9 - Statewide Community Council Meeting, Portage.

Feb. 17 - Meeting on infant mortality, Beloit.

Collaborations

- Association of SIDS and Infant Mortality Program Professionals.
- Beloit African American Infant

- Mortality Coalition.
- Fetal Concerns Program.
- Great Lakes Intertribal Council Honoring Our Children Project.
- Healthy Babies in Wisconsin Steering Committee and Regional Action Teams.
- La Causa.
- March of Dimes.
- Milwaukee Area Hospital Collaborative.
- Milwaukee County Child Fatality Review Team.
- Milwaukee Fetal Infant Mortality Review Project.
- Milwaukee Healthy Beginnings Steering Committee, Data Evaluation Committee and Consortium.
- Milwaukee Tobacco Free Task Force and Faith Based Community Health Committee.
- Racine County Death Review Team.
- Family Resource Center of Sherman Park.
- State of Wisconsin Bureau of Health Information.
- State of Wisconsin Division of Public Health.
- Supporting First Time Parents.
- Waukesha County Child Fatality Review Team.
- Wisconsin Association for Perinatal Care.
- Wisconsin Child Care Resource and Referral Network.
- Wisconsin Early Childhood Association.
- Wisconsin Maternal and Child Health Coalition.
- Wisconsin Public Health Association.

Northern/Western Region

Dora Gorski: (715) 843-1877

Educational programs

Jan. 26 - Presentation to Women, Infants and Children on American Academy of Pediatrics recommendations and media site/new training CD.

Informational exhibits

Dec. 7 - Display at New Beginnings Birthing Center open house - Aspirus

Hospital, Wausau.
Jan. 4 - Display at New Beginnings Birthing Center open house - Aspirus Hospital, Wausau.
Feb. 1 - Display at New Beginnings Birthing Center open house - Aspirus Hospital, Wausau.

Support to families

Dec. 8 - Candle Light Holiday Memorial meeting of SAID Group.

The SAID Group meets the second Thursday of every month at Children's Service Society of Wisconsin in Wausau.

Other

Dec. 7 - Western Regional Community Council Meeting via conference call.
Dec. 9 - Statewide Community Council Meeting - Portage meeting with Marcia Hagen HoChunk community health nurse, Black Earth.

Jan. 12 - Child Fatality Review Team Meeting, Marathon County.

Jan. 18 - Attended Presentation of "Life in Marathon County 2005-2007" report from the community planning council.

Feb. 15 - Western Healthy Babies Action Team Meeting, Eau Claire.

Feb. 23-24 - CJ Foundation National SIDS Conference, Philadelphia.

Feb. 27 - Northern Region Community Council Meeting, Wausau.

March 6 - Western Regional Community Council Meeting via conference call.

Northeastern Region

Educational programs

Anne Harvieux: (414) 266-2746

Sept. 27 - Marian College Nursing Students.

Sept. 28 - Marian College Nursing Students.

Oct. 19 - NWTC SIDS training for health care professionals, Green Bay.

Oct. 26 - Northeast Regional Healthy Babies Action Team.

Nov. 16 - Marian College Nursing Students.

Nov. 29 - Marian College Nursing Students.

Dec. 14 - Family Health La Clinica, Wautoma.

Dec. 19 - NWTC SIDS training for health care professionals.
 Dec. 21 - Hmong American Partnership, Appleton.
 Feb. 6 - Family Health La Clinica, Wautoma.
 Feb. 28 - Northeast Regional Healthy Babies Action Team.
 March 16 - B.A.B.E.S., Inc., Appleton.
Support to Families
 Oct. 16 - 4th Annual Walk to Remember, Appleton.
 Dec. 7 - Candlelight Memorial Program, Neenah.
 A support group for families meets at 7

p.m. every fourth Tuesday of the month. For information, call (414) 266-2745.

Collaborations

- Hispanic Interagency Council, Fox Valley.
- Hmong Interagency Council, Fox Valley.
- Great Lakes Intertribal Council - Honoring Our Children Project.
- Fox Valley Grief Network.
- Center for Grieving Children
- Safe Kids
- B.A.B.E.S. Inc.
- Family Health La Clinica

Meetings

Dec. 9 - Infant Death Center of Wisconsin State Council meeting.
 Jan. 19 - Fox Valley Grief Network.
 Jan. 19 - Hmong Interagency Council.
 Jan. 25 - Northeast Regional Council meeting.
 Feb. 2 - Hispanic Interagency Council.
 Feb. 16 - Hispanic Interagency Council.
 Feb. 22-24 - National SIDS Conference, Philadelphia.
 March 2 - Hispanic Interagency Council.
 March 16 - Hmong Interagency Council.

Lighting the Way continued from Page 2

The mission of this conference is to help families develop the ability to integrate the death of their infants into their lives and increase their coping skills. A number of alternatives are available to assist individuals and families in networking and developing ways to cope with the death of a child. We encourage you to take a break, take time for yourself to think, release stress or just relax.

More about the speaker: Olon Lindemood is a bereaved parent who has used sharing with other bereaved parents as a tool to express his grief following the death of his daughter, Betsy. He has walked the journey of grief and has shared his journey through his presentations at conferences and memorial programs.

The cost of the event is \$20 for adults and \$5 for children. The fee includes a continental breakfast, lunch, conference materials and child care.

Agenda

Friday, April 7

7 p.m. - 9 p.m. Registration and optional craft session for families

Saturday, April 8

8 a.m. Registration
 8:25 a.m. Opening session
 9:45 a.m. Sharing program
 10:30 a.m. Break
 10:45 a.m. Breakout session one
 11:45 a.m. Lunch
 12:45 p.m. Memorial program
 1:45 p.m. Breakout session two
 3:30 p.m. Closing session and bubble release

Yes, I wish to register for the *Lighting the Way* conference.

Name: _____

Address: _____

Number of adults attending: _____ Number of children attending: _____

I will be using child care (please circle one): Yes No

I have enclosed a check payable to the Infant Death Center of Wisconsin in the amount of \$ _____

Return this form with your registration fee to the Infant Death Center of Wisconsin, P.O. Box 1997, MS C630, Milwaukee, WI 53201-1997.

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, 2005, and Jan. 31, 2006.

In memory of:

Alex Amundson

Dick and Peggy Larsen

Erik Baumler

Mr. and Mrs. Brian R. Baumler
Mr. and Mrs. Richard Baumler

Christopher William Beno

Mr. and Mrs. Mark T. Beno

Vincent Paul Cannariato

Col. Pops Popcorn Co.

David Joseph Crawford

Mr. Albert C. Lewis

Sheila Groth

Anonymous
A Gift of Time, Inc.
Mr. James I. Adams
Mr. and Mrs. Michael J. Adams
Swaranjit and Nirmala Arora
Ms. Laura Bianco
Gene L. Bodwin
Mr. and Mrs. Scott M. Brattebo
Mrs. Susan T. Burns
Mr. and Mrs. Stuart S. Carlson
L. M. Charnitz
Mr. and Mrs. Paul H. Clithero
Ms. Shirley G. Cohen
Mr. and Mrs. William L. Cook II
Mr. and Mrs. Philip J. Czarnecki
Ms. Jeannine T. Dwyer
Ms. Margaret Evans
Evans Transportation Services, Inc.
Ms. Rosalie Glanz
Gloudeman Family
Tim and Mary Sue Graf
Ms. Dorothy Horkey
Ms. Joann A. Hungelmann
Ms. Joann F. Jackson
Ms. Paula Jandourek

Mr. Jeffrey Killberg
Mr. and Mrs. Robert Klessig
Friends at M&I Bank
Mr. and Mrs. Robert R. Maccani
Mr. and Mrs. Micheal S. Maierle
Mr. and Mrs. Kevin J. Mailey
Mr. Richard Malverson
Mr. and Mrs. Linc Mann
Thomas J. McGovern and Wendy Stolt
Mr. and Mrs. William R. McGovern III
Ms. Gail C. Piche
Mr. Mark T. Provost
Mrs. and Mrs. Mitchell W. Quick
Frances J. Riley
Ms. Gina Romaine
Mr. and Mrs. James H. Rowe
Mr. and Mrs. John J. Ryan
Ms. Gayle A. Rzany
Mr. and Mrs. John J. Siebenlist
Ms. Lois P. Smith
Mr. and Mrs. John Speaker
St. Joseph Regional Medical Ct. Care Management Dept.
St. Mary's Congregation
Mr. and Mrs. Herb Steffes
Ms. Virginia M. Stone
The Pasha Group
Mrs. Lois Thompson
Mr. and Mrs. George J. Vistain
Ms. Dorothy Weingrod
Thomas and Dana Wieggers
Ms. Laura Wiesmueller
Mr. and Mrs. Dean M. Wolter
Ms. Gerry Woody
Mr. and Mrs. Kevin M. Ziegler

Celine Elizabeth Groves

Mr. and Mrs. Rodney J. Holzschuh

Kera Jo Haase

Mr. and Mrs. Kevin R. Colwell
Mr. and Mrs. Bruce A. Otterberg

Patrick Forest Harrington

Reverend and Mrs. James L. Harrington

Chavala Madeline Pilmaier

Great Grandma and Grandpa Pilmaier

Doris Reese

Mr. and Mrs. Terrance Busshardt
Ms. Sherry Christian
Mr. and Mrs. Anthony D. Pauli
Sally R. Wilson & Doris Reese

Madeline R. Thorpe

Mr. and Mrs. Daniel N. Burnside

In honor of:

Matthew Groth

Ms. Laura Wiesmueller

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.

Will it ever be spring, continued from Page 1

a bit like buying a snow shovel and leaning it against the garage door. The snow doesn't get moved unless we do it. It will snow anywhere, regardless of how much we shake our fists or sigh or cry. The winter comes and stays and stays and stays and IT can take up permanent residence if we let it. But waiting and hoping won't re-warm the earth. Shoveling snow warms the body and keeps us limber in preparation for the return of spring.

Reading seed catalogs won't get the seeds planted, but it will keep the mind busy and the dreaming spaces alive in the heart. Grief is work, not merely marking the passing of time. Shoveling snow and dyeing Easter eggs and planning the garden are work, too. And time seems to move faster when we move faster.

Waiting for IT to melt doesn't seem to have much effect. But, facing the snow with a determined shovel, planning the garden with a hopeful eye and living through the winter storms of grief all seem to lead us to the spring season where memory becomes softer and we begin to understand that we, too, are someone new. The calendar says it's spring, and so it is. If IT remains in your heart, take care and nurture yourself as gently as you water and tender earth. If there still is snow on your spring parade, wear boots instead of sandals and remember that you are not alone. Somewhere, some place, someone else also is struggling to make sense out of the rhythms of life. We don't have to know why in order to ask how – how to shovel snow, how to dye eggs, how to plant

seeds, how to live with the empty spaces. Just know you have to search for the answers yourself. They won't come to you in the magic of wishes, but they can come if you will look.

We cannot fill up the empty spaces left by loved ones, but the snow begins to melt when we realize that love creates new spaces in the heart and expands the spirit and deepens the joy of simply being alive.

Look for the spring, demand it for yourself. Let some of the ice go. Find some of the happiness that your loved one brought to your life, and let that light warm the seeds of healing. Your loved one brought light to your life, don't lose that in the continued winter of despair. Waiting and hoping aren't enough. Grief is work, but the springtime earth is softer and the shoveling is easier. ❖



Reprinted with permission from Darcie D. Sims, If I Could Just See Hope, 1993, Big A & Company.

Wisconsin Perspectives is the newsletter of the Infant Death Center of Wisconsin. The goal of this newsletter is to provide information to help reduce infant deaths and improve infant health.

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. With any questions or comments about the program or newsletter, contact Anne Harvieux, program administrator, at (414) 266-2746 or aharvieux@chw.org.

To reach the center and the South/Southeastern regional office, contact Anne Harvieux at (414) 266-2746 or aharvieux@chw.org or Vivian Jackson at (414) 266-2745 or vjackson@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.

New arrivals:

Congratulations to the following families on their new additions:

Cayla Noelle Ceplina was born Dec. 25, 2005 to Melissa Ceplina.

Alicyn Hope Klapper was born Oct. 27, 2005 to Jon and Brandi Klapper.



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



Children's Hospital
of Wisconsin®

A member of Children's Hospital and Health System.

Children's Hospital of Wisconsin, Inc.
PO Box 1997
Milwaukee, WI 53201-1997

Non-Profit
Organization
U. S. POSTAGE
PAID
Milwaukee, WI
Permit No. 2284