

**Senate Counsel, Research,
and Fiscal Analysis**

G-17 STATE CAPITOL
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Senate

State of Minnesota

**S.F. No. 1279 - Prior Authorization for Antihemophilic Factor
Drugs Under the Medical Assistance**

Author: Senator D. Scott Dibble

Prepared by: Katie Cavanor, Senate Counsel (651/296-3801) *KTC*

Date: April 8, 2005

S.F. No. 1279 would prohibit the Department of Human Services from requiring or utilizing prior authorization for any antihemophilic factor drug where there is no generically equivalent drug available as part of the supplemental drug rebate program or preferred drug list. (Currently, this prohibition expires July 1, 2005. Under this bill, this expiration date would be removed.)

KC:ph

Senators Dibble and Lourey introduced--

S.F. No. 1279: Referred to the Committee on Health and Family Security.

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A bill for an act

relating to human services; removing the sunset for a provision exempting certain antihemophilic factor drugs from prior authorization under medical assistance; amending Minnesota Statutes 2004, section 256B.0625, subdivision 13f.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF MINNESOTA:

Section 1. Minnesota Statutes 2004, section 256B.0625, subdivision 13f, is amended to read:

Subd. 13f. [PRIOR AUTHORIZATION.] (a) The Formulary Committee shall review and recommend drugs which require prior authorization. The Formulary Committee shall establish general criteria to be used for the prior authorization of brand-name drugs for which generically equivalent drugs are available, but the committee is not required to review each brand-name drug for which a generically equivalent drug is available.

(b) Prior authorization may be required by the commissioner before certain formulary drugs are eligible for payment. The Formulary Committee may recommend drugs for prior authorization directly to the commissioner. The commissioner may also request that the Formulary Committee review a drug for prior authorization. Before the commissioner may require prior authorization for a drug:

(1) the commissioner must provide information to the Formulary Committee on the impact that placing the drug on prior authorization may have on the quality of patient care and on

1 program costs, information regarding whether the drug is subject
2 to clinical abuse or misuse, and relevant data from the state
3 Medicaid program if such data is available;

4 (2) the Formulary Committee must review the drug, taking
5 into account medical and clinical data and the information
6 provided by the commissioner; and

7 (3) the Formulary Committee must hold a public forum and
8 receive public comment for an additional 15 days.

9 The commissioner must provide a 15-day notice period before
10 implementing the prior authorization.

11 (c) Prior authorization shall not be required or utilized
12 for any atypical antipsychotic drug prescribed for the treatment
13 of mental illness if:

14 (1) there is no generically equivalent drug available; and

15 (2) the drug was initially prescribed for the recipient
16 prior to July 1, 2003; or

17 (3) the drug is part of the recipient's current course of
18 treatment.

19 This paragraph applies to any multistate preferred drug list or
20 supplemental drug rebate program established or administered by
21 the commissioner.

22 (d) Prior authorization shall not be required or utilized
23 for any antihemophilic factor drug prescribed for the treatment
24 of hemophilia and blood disorders where there is no generically
25 equivalent drug available if the prior authorization is used in
26 conjunction with any supplemental drug rebate program or
27 multistate preferred drug list established or administered by
28 the commissioner. ~~This paragraph expires July 17, 2005.~~

29 (e) The commissioner may require prior authorization for
30 brand name drugs whenever a generically equivalent product is
31 available, even if the prescriber specifically indicates
32 "dispense as written-brand necessary" on the prescription as
33 required by section 151.21, subdivision 2.

34 [EFFECTIVE DATE.] This section is effective June 30, 2005.

April 4, 2005
Reference No.: SITF05017

Honorable Becky Lourey
Chair, Health & Family Security Committee
Minnesota State Senate
75 Rev. Dr. Martin Luther King Jr. Blvd.
Room G-24
St. Paul, MN 55155-1606

RE: Senate File 1279 – Medical assistance anti-hemophilic factor drugs prior authorization requirement exemption permanency

Dear Senator Lourey:

On behalf of the Plasma Protein Therapeutics Association (PPTA), I am writing to thank you for co-authoring Senate File 1279, along with Senator Scott Dibble. If enacted, SF 1279 would indefinitely extend the statutory prohibition on imposition of prior authorization requirements for anti-hemophilic blood clotting factor therapies provided to beneficiaries of the Minnesota Medical Assistance programs. I am also writing to ask that the Health & Family Security Committee consider and approve SF 1279 as soon as possible. Under current law, this prohibition on imposition of prior authorization requirements is set to expire on June 30, 2005.

PPTA is the primary advocate for the world's leading producers of plasma-derived and recombinant blood clotting factor therapies. These life-saving therapies are used by millions of people to treat a variety of diseases and serious medical conditions, including hemophilia and von Willebrand's disease.

It is crucial as a matter of public policy that the beneficiaries within the Minnesota medical assistance programs who have hemophilia never be denied timely access to the treatments they need to keep them alive and functioning. Any attempt to apply prior authorization requirements to blood clotting factor therapies could have dire consequences for the patients relying on these therapies, and could result in death. A patient experiencing a bleeding episode who is in need of a blood-clotting therapy cannot wait the time that prior authorization could take to approve or deny his or her therapy. Delayed access to clotting factor can cause painful and crippling injury to a hemophiliac's joints and organs, and could cause death. This is likely to result in a significant cost-shifting to hospitals, skilled nursing care centers and other specialty providers.

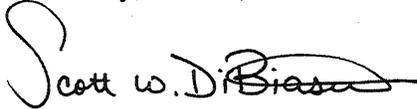
Indefinite extension of the existing statutory prohibition on prior authorization for the drugs and therapies used to treat hemophilia is the only way to permanently assure that all patients in Minnesota who rely on life-saving blood clotting factor therapies continue to have access to them without unnecessary delay or administrative requirements.

Further, indefinite extension of the prior authorization prohibition would have no fiscal impact to the State of Minnesota. The lack of fiscal impact is due to the fact that, in the event that prior authorization were implemented for blood clotting factor therapies, 99% of any prior authorization requests would be approved by the agency reviewing the requests and the therapy would be dispensed. In addition, spending on blood clotting factor therapies within the Minnesota medical assistance programs in 2003 totaled less than 2% of the overall spending on prescription drugs & therapies.

For these reasons, PPTA requests that the Senate Health & Family Security Committee consider, and approve, SF 1279 as soon as possible.

Thank you again for co-sponsoring SF 1279 and we sincerely appreciate your timely consideration of this request. If you should have any questions, please contact me at (202) 789-3100 or Mr. Randy Morris at (612) 338-2525.

Sincerely,



Scott W. DiBiasio
Senior Manager, State Affairs

cc: Mr. James Paist, Hemophilia Foundation of Minnesota/Dakotas

April 1, 2005

Senator Becky Lourey
G-24 Capitol
75 Rev. Dr. Martin Luther King Jr. Blvd.
Saint Paul, Minnesota 55155

Re: SF1279

Dear Senator Lourey;

I am writing to ask for your support for Senate File 1279. This bill, amending Minnesota Statutes 2004, section 256B.0625, subdivision 13f. removes the sunset for a provision exempting factor medications (for the treatment of hemophilia) from prior authorization under Medical Assistance. The current provision will expire July 1, 2005. *See attached copy of HF855, line 2.28.*

The Hemophilia Foundation of Minnesota and the Dakotas (HFMD) represents the thousands of individuals in this State that are affected by hemophilia and other bleeding disorders. People who have hemophilia rely on rapid access to these factor medications to stop internal bleeding, delays in the administration of these medications can be life threatening. Maintaining this current exemption from prior authorization helps to ensure access to these medications without undue administrative delay.

Your support for this bill will be greatly appreciated not only by this organization, but by the many Minnesotans who rely on State programs for their health care.

Sincerely,

James Paist
Executive Director
HFMD

**Senate Counsel, Research,
and Fiscal Analysis**

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Senate
State of Minnesota

**S.F. No. 1029 - Record of Stillbirth
(Delete-Everything Amendment)**

Author: Senator Ellen R. Anderson

Prepared by: Katie Cavanor, Senate Counsel (651/296-3801) KC

Date: April 8, 2005

S.F. No. 1029 creates the ability for parents of a stillbirth to be able to request a certificate of birth resulting in a stillbirth.

Section 1 (144.2151) establishes a record of stillbirth.

Subdivision 1 requires a record of birth for each birth resulting in a stillbirth for which a fetal death report is required to be filed with the State registrar within five days after the birth if the parent wishes to have a record of birth resulting in stillbirth prepared.

Subdivision 2 requires the party responsible for filing a fetal death report to advise the parent of a stillbirth that:

- (1) they may request a record of birth resulting in stillbirth be prepared;
- (2) that preparation of the record is optional; and
- (3) how to obtain a certified copy of the record if one is requested and prepared.

Subdivision 3 requires the party responsible for filing a fetal death report to prepare and file the record with the State registrar if the parent wishes a record of birth resulting in stillbirth prepared. If the parent does not want to provide a name for the stillbirth, the name shall be left blank on the record of birth resulting in stillbirth. Either parent of the stillbirth or if neither parent is available, another person with knowledge of the facts shall attest to the accuracy of data entered on the record in time to permit filing within five days after deliver.

Subdivision 4 states that if a birth that occurred at any time resulted in a stillbirth that required a fetal death report but a record of birth resulting in stillbirth was not prepared, a parent of the stillbirth may submit to the State registrar on or after August 1, 2005, a written request for preparation of a record of birth resulting in stillbirth and provide evidence of facts of the stillbirth in a form specified by the State registrar. The State registrar shall prepare and file the record within 30 days of receiving satisfactory evidence of the facts of the stillbirth.

Subdivision 5 requires the State registrar to:

- (1) prescribe the form and information to be included on the record;
- (2) prescribe the form and information to be provided by the parent of a stillbirth requesting a record of birth resulting in stillbirth retroactively; and
- (3) issue a certified copy of a record of birth resulting in stillbirth to a parent if a record has been prepared and filed and the parent is requesting a certified copy and submits the request in writing.

Section 2 (144.212, subdivision 8) adds to the definition of “vital record” a record of stillbirth.

Section 3 (144.222, subdivision 1) states that a fetal death report must be filed within five days of the death of a fetus for whom 20 or more weeks of gestation have elapsed, except for abortions as defined under section 145.4241. Requires this report to be filed by:

- (1) the person in charge of an institution or a designee if a fetus is delivered in the institution or en route to the institution;
- (2) a health care professional in attendance at or immediately after the deliver if the fetus is delivered outside an institution; or
- (3) a parent or person in charge of the disposition of the remains if a fetal death occurred without medical attendance at or immediately after the delivery.

Section 4 (144.226, subdivision 1) permits a fee to be charged for the issuance of a certified stillbirth record. (Making it the same as for a birth or death record)

Section 5 (144.226, subdivision 3) permits a surcharge to be charged for each certified stillbirth record. (Making it the same as for a birth or death record.)

Section 6 (144.226, subdivision 4) permits an additional surcharge to be charged for each certified and noncertified stillbirth record. (Making it the same as for a birth or death record.)

Section 7 repeals Minnesota Rules, part 4601.2200, subpart 1, which is codified in **section 3**.

KC:ph

Senators Bachmann; Johnson, D.J. and Robling introduced--

S.F. No. 1029: Referred to the Committee on Health and Family Security.

1 A bill for an act

2 relating to health; providing for an optional record
3 of birth resulting in stillbirth; amending Minnesota
4 Statutes 2004, section 144.222, subdivision 1;
5 proposing coding for new law in Minnesota Statutes,
6 chapter 144.

7 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF MINNESOTA:

8 Section 1. [144.2151] [RECORD OF STILLBIRTH.]

9 Subdivision 1. [FILING.] A record of birth for each birth
10 resulting in a stillbirth in this state, on or after August 1,
11 2005, for which a fetal death report is required under section
12 144.222, subdivision 1, shall be filed with the state registrar
13 within five days after the birth if the parent or parents of the
14 stillbirth wish to have a record of birth resulting in
15 stillbirth prepared.

16 Subd. 2. [INFORMATION TO PARENTS.] The party responsible
17 for filing a fetal death report under section 144.222,
18 subdivision 1, shall advise the parent or parents of a
19 stillbirth:

20 (1) that they may request preparation of a record of birth
21 resulting in stillbirth;

22 (2) that preparation of the record is optional; and

23 (3) how to obtain a certified copy of the record if one is
24 requested and prepared.

25 Subd. 3. [PREPARATION.] (a) Within five days after
26 delivery of a stillbirth, the party responsible for filing a

1 fetal death report under section 144.222, subdivision 1, shall
2 prepare and file the record with the state registrar if the
3 parent or parents of the stillbirth, after being advised as
4 provided in subdivision 2, wish to have a record of birth
5 resulting in stillbirth prepared.

6 (b) If the parent or parents of the stillbirth do not wish
7 to provide a name for the stillbirth, the person who prepares
8 the record of birth resulting in stillbirth shall leave blank
9 any reference to the name of the stillbirth.

10 (c) Either parent of the stillbirth or, if neither parent
11 is available, another person with knowledge of the facts of the
12 stillbirth shall attest to the accuracy of the personal data
13 entered on the record in time to permit the filing of the record
14 within five days after delivery.

15 Subd. 4. [RETROACTIVE APPLICATION.] Notwithstanding
16 subdivisions 1 to 3, if a birth that occurred in this state at
17 any time resulted in a stillbirth for which a fetal death report
18 was required under section 144.222, subdivision 1, but a record
19 of birth resulting in stillbirth was not prepared under
20 subdivision 3, a parent of the stillbirth may submit to the
21 state registrar, on or after August 1, 2005, a written request
22 for preparation of a record of birth resulting in stillbirth and
23 evidence of the facts of the stillbirth in the form and manner
24 specified by the state registrar. The state registrar shall
25 prepare and file the record of birth resulting in stillbirth
26 within 30 days after receiving satisfactory evidence of the
27 facts of the stillbirth.

28 Subd. 5. [RESPONSIBILITIES OF STATE REGISTRAR.] The state
29 registrar shall:

30 (1) prescribe the form of and information to be included on
31 a record of birth resulting in stillbirth, which shall be as
32 similar as possible to the form of and information included on a
33 record of birth;

34 (2) prescribe the form of and information to be provided by
35 the parent of a stillbirth requesting a record of birth
36 resulting in stillbirth under subdivision 4; and

1 (3) issue a certified copy of a record of birth resulting
2 in stillbirth to a parent of the stillbirth that is the subject
3 of the record if:

4 (i) a record of birth resulting in stillbirth has been
5 prepared and filed under subdivision 3 or 4; and

6 (ii) the parent requesting a certified copy of the record
7 submits the request in writing.

8 Sec. 2. Minnesota Statutes 2004, section 144.222,
9 subdivision 1, is amended to read:

10 Subdivision 1. [~~FETAL DEATH REPORT REQUIRED.~~] ~~Each-fetal~~
11 ~~death-which-occurs-in-this-state-shall-be-reported-within-five~~
12 ~~days-to-the-state-registrar-as-prescribed-by-rule-by-the~~
13 ~~commissioner.~~ A fetal death report must be filed within five
14 days of the death of a fetus for whom 20 or more weeks of
15 gestation have elapsed, except for abortions subject to the
16 reporting requirements under section 145.4131. A fetal death
17 report shall be filed by:

18 (1) a person in charge of an institution or that person's
19 authorized designee if a fetus is delivered in the institution
20 or en route to the institution;

21 (2) a physician, certified nurse midwife, or other licensed
22 medical personnel in attendance at or immediately after the
23 delivery if a fetus is delivered outside an institution; or

24 (3) a parent or other person in charge of the disposition
25 of the remains if a fetal death occurred without medical
26 attendance at or immediately after the delivery.

1 Senator moves to amend S.F. No. 1029 as follows:

2 Delete everything after the enacting clause and insert:

3 "Section 1. [144.2151] [RECORD OF STILLBIRTH.]

4 Subdivision 1. [FILING.] A record of birth for each birth
5 resulting in a stillbirth in this state, on or after August 1,
6 2005, for which a fetal death report is required under section
7 144.222, subdivision 1, shall be filed with the state registrar
8 within five days after the birth if the parent or parents of the
9 stillbirth wish to have a record of birth resulting in
10 stillbirth prepared.

11 Subd. 2. [INFORMATION TO PARENTS.] The party responsible
12 for filing a fetal death report under section 144.222,
13 subdivision 1, shall advise the parent or parents of a
14 stillbirth:

15 (1) that they may request preparation of a record of birth
16 resulting in stillbirth;

17 (2) that preparation of the record is optional; and

18 (3) how to obtain a certified copy of the record if one is
19 requested and prepared.

20 Subd. 3. [PREPARATION.] (a) Within five days after
21 delivery of a stillbirth, the parent or parents of the
22 stillbirth shall prepare and file the record with the state
23 registrar if the parent or parents of the stillbirth, after
24 being advised as provided in subdivision 2, wish to have a
25 record of birth resulting in stillbirth prepared.

26 (b) If the parent or parents of the stillbirth do not wish
27 to provide a name for the stillbirth, the parent or parents of
28 the stillbirth shall file only a last name for the stillbirth.

29 (c) Either parent of the stillbirth or, if neither parent
30 is available, another person with knowledge of the facts of the
31 stillbirth shall attest to the accuracy of the personal data
32 entered on the record in time to permit the filing of the record
33 within five days after delivery.

34 Subd. 4. [RETROACTIVE APPLICATION.] Notwithstanding
35 subdivisions 1 to 3, if a birth that occurred in this state at
36 any time resulted in a stillbirth for which a fetal death report

1 was required under section 144.222, subdivision 1, but a record
2 of birth resulting in stillbirth was not prepared under
3 subdivision 3, a parent of the stillbirth may submit to the
4 state registrar, on or after August 1, 2005, a written request
5 for preparation of a record of birth resulting in stillbirth and
6 evidence of the facts of the stillbirth in the form and manner
7 specified by the state registrar. The state registrar shall
8 prepare and file the record of birth resulting in stillbirth
9 within 30 days after receiving satisfactory evidence of the
10 facts of the stillbirth.

11 Subd. 5. [RESPONSIBILITIES OF STATE REGISTRAR.] The state
12 registrar shall:

13 (1) prescribe the form of and information to be included on
14 a record of birth resulting in stillbirth, which shall be as
15 similar as possible to the form of and information included on a
16 record of birth;

17 (2) prescribe the form of and information to be provided by
18 the parent of a stillbirth requesting a record of birth
19 resulting in stillbirth under subdivisions 3 and 4 and make this
20 form available on the Department of Health's Web site;

21 (3) issue a certified copy of a record of birth resulting
22 in stillbirth to a parent of the stillbirth that is the subject
23 of the record if:

24 (i) a record of birth resulting in stillbirth has been
25 prepared and filed under subdivision 3 or 4; and

26 (ii) the parent requesting a certified copy of the record
27 submits the request in writing; and

28 (4) create and implement a process for entering, preparing,
29 and handling stillbirth records identical or as close as
30 possible to the processes for birth and fetal death records when
31 feasible, but no later than the date on which the next
32 reprogramming of the Department of Health's database for vital
33 records is completed.

34 Sec. 2. Minnesota Statutes 2004, section 144.212,
35 subdivision 8, is amended to read:

36 Subd. 8. [VITAL RECORD.] "Vital record" means a record or

1 report of birth, stillbirth, death, marriage, dissolution and
2 annulment, and data related thereto. The birth record is not a
3 medical record of the mother or the child.

4 Sec. 3. Minnesota Statutes 2004, section 144.222,
5 subdivision 1, is amended to read:

6 Subdivision 1. [FETAL DEATH REPORT REQUIRED.] ~~Each-fetal~~
7 ~~death-which-occurs-in-this-state-shall-be-reported-within-five~~
8 ~~days-to-the-state-registrar-as-prescribed-by-rule-by-the~~
9 ~~commissioner.~~ A fetal death report must be filed within five
10 days of the death of a fetus for whom 20 or more weeks of
11 gestation have elapsed, except for abortions defined under
12 section 145.4241. A fetal death report must be prepared in a
13 format prescribed by the state registrar and filed in accordance
14 with Minnesota Rules, parts 4601.0100 to 4601.2600 by:

15 (1) a person in charge of an institution or that person's
16 authorized designee if a fetus is delivered in the institution
17 or en route to the institution;

18 (2) a physician, certified nurse midwife, or other licensed
19 medical personnel in attendance at or immediately after the
20 delivery if a fetus is delivered outside an institution; or

21 (3) a parent or other person in charge of the disposition
22 of the remains if a fetal death occurred without medical
23 attendance at or immediately after the delivery.

24 Sec. 4. Minnesota Statutes 2004, section 144.226,
25 subdivision 1, is amended to read:

26 Subdivision 1. [WHICH SERVICES ARE FOR FEE.] The fees for
27 the following services shall be the following or an amount
28 prescribed by rule of the commissioner:

29 (a) The fee for the issuance of a certified vital record or
30 a certification that the vital record cannot be found is \$8. No
31 fee shall be charged for a certified birth, stillbirth, or death
32 record that is reissued within one year of the original issue,
33 if an amendment is made to the vital record and if the
34 previously issued vital record is surrendered.

35 (b) The fee for the replacement of a birth record for all
36 events, except when filing a recognition of parentage pursuant

1 to section 257.73, subdivision 1, is \$20.

2 (c) The fee for the filing of a delayed registration of
3 birth, stillbirth, or death is \$20.

4 (d) The fee for the amendment of any vital record when
5 requested more than 45 days after the filing of the vital record
6 is \$20. No fee shall be charged for an amendment requested
7 within 45 days after the filing of the vital record.

8 (e) The fee for the verification of information from vital
9 records is \$8 when the applicant furnishes the specific
10 information to locate the vital record. When the applicant does
11 not furnish specific information, the fee is \$20 per hour for
12 staff time expended. Specific information includes the correct
13 date of the event and the correct name of the registrant. Fees
14 charged shall approximate the costs incurred in searching and
15 copying the vital records. The fee shall be payable at the time
16 of application.

17 (f) The fee for issuance of a copy of any document on file
18 pertaining to a vital record or statement that a related
19 document cannot be found is \$8.

20 Sec. 5. Minnesota Statutes 2004, section 144.226,
21 subdivision 3, is amended to read:

22 Subd. 3. [BIRTH RECORD SURCHARGE.] In addition to any fee
23 prescribed under subdivision 1, there shall be a nonrefundable
24 surcharge of \$3 for each certified birth or stillbirth record
25 and for a certification that the vital record cannot be found.
26 The local or state registrar shall forward this amount to the
27 commissioner of finance for deposit into the account for the
28 children's trust fund for the prevention of child abuse
29 established under section 119A.12. This surcharge shall not be
30 charged under those circumstances in which no fee for a
31 certified birth or stillbirth record is permitted under
32 subdivision 1, paragraph (a). Upon certification by the
33 commissioner of finance that the assets in that fund exceed
34 \$20,000,000, this surcharge shall be discontinued.

35 Sec. 6. Minnesota Statutes 2004, section 144.226,
36 subdivision 4, is amended to read:

1 Subd. 4. [VITAL RECORDS SURCHARGE.] In addition to any fee
2 prescribed under subdivision 1, there is a nonrefundable
3 surcharge of \$2 for each certified and noncertified birth,
4 stillbirth, or death record, and for a certification that the
5 record cannot be found. The local or state registrar shall
6 forward this amount to the commissioner of finance to be
7 deposited into the state government special revenue fund. This
8 surcharge shall not be charged under those circumstances in
9 which no fee for a birth, stillbirth, or death record is
10 permitted under subdivision 1, paragraph (a).

11 Sec. 7. [REPEALER.]

12 Minnesota Rules, part 4601.2200, subpart 1, is repealed."

13 Amend the title as follows:

14 Page 1, line 4, delete everything after the first comma

15 Page 1, delete lines 5 and 6 and insert "sections 144.212,
16 subdivision 8; 144.222, subdivision 1; 144.226, subdivisions 1,
17 3, 4; proposing coding for new law in Minnesota Statutes,
18 chapter 144; repealing Minnesota Rules, part 4601.2200, subpart
19 1."

Testimonial for Optional Record of Birth Resulting in Stillbirth (SF1029)
Minnesota State Capitol
April 12, 2005

Speaker: Susan Lacek, Bereaved Mother

After a normal, uneventful pregnancy, my husband Mark and I were eagerly awaiting the birth of our first child. As other expectant parents, we looked forward to her upcoming arrival with joyful anticipation, believing this would be the happiest time of our lives. Instead, it became the darkest.

Three weeks before our due date in June of 2000, we received the shocking news that our baby had died and no one could explain why. Upon her birth, it became apparent that our daughter, Faith Ann Lacek, had become the victim of an umbilical cord accident. Our world was shattered.

The nursing staff at Fairview Southdale Hospital tried to help us through our darkest hours. They lovingly dressed our daughter, took photos of her and presented us with special mementos. One of these items was a "Keepsake Birth Certificate." While we value this document and still keep it proudly displayed to this day, it saddened us that we were not able to receive a legal document that proved her birth and existence. Although she never took a breath on this earth, our daughter was and continues to be a very real and important person to us. She is a part of our family that we will never forget. Her photo is displayed in our home next to our living children's, and at Christmas time, her stocking hangs along with the rest of the family's on the mantel. She is a real person yet the State of Minnesota has not acknowledged her birth. *We are here today to ask you to change this - for us as well as all the other bereaved parents who will, sadly but most certainly, come after us.*

It is time for Minnesota to join the other eleven states that have already passed similar legislation enabling parents who have lost a full-term baby during the pregnancy and birth process to receive a birth certificate for stillbirth. As such, we ask that this bill be passed today so that Minnesota bereaved parents can respectfully and rightfully recognize their child's existence on this earth and in their lives.

Thank you for your consideration.

Respectfully,

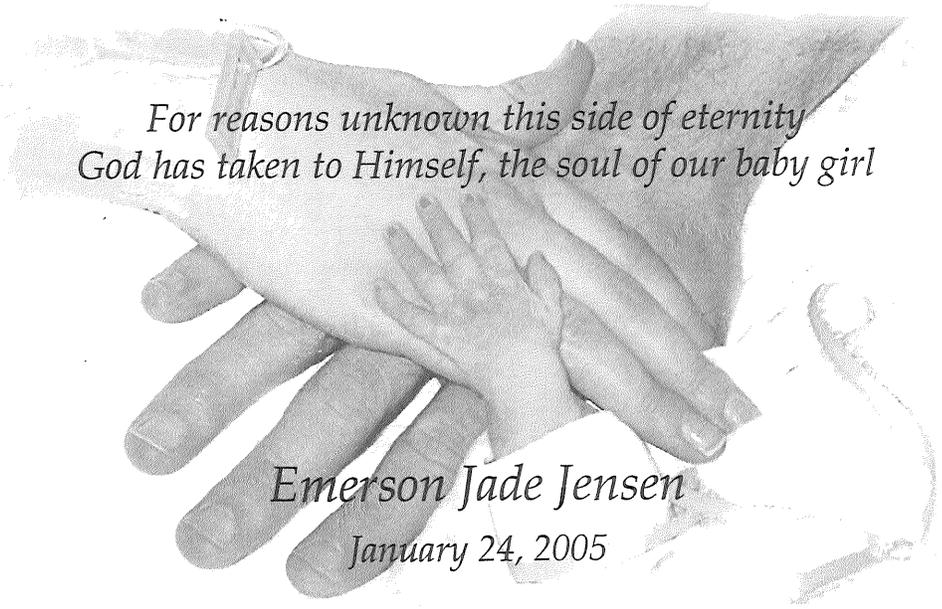


Susan Lacek
Mother to Baby Faith

4348 Fremont Avenue South
Minneapolis, MN 55409
Phone: 612-823-5265
Email: Susanlacek@aol.com

We respectfully ask that you pass the The Missing Angels Bill
in memory of Faith Ann Lacek (stillborn June 5, 2000)
and all other babies stillborn in the State of Minnesota.





*For reasons unknown this side of eternity
God has taken to Himself, the soul of our baby girl*

Emerson Jade Jensen

January 24, 2005

Cameron and Kyle

Our daughter's life was valuable, and her birth was very real. As parents of a stillborn child we hope that you will allow her birth to be validated. We made plans for her and we still love her. Please help us with our healing process by allowing us to have a certificate of birth along with her certificate of death.

Cameron & Kyle Jensen

Minnesota Missing Angel Bill- 2005

All I ever wanted to be was a mother. Everything in my life was leading up to that goal. I went to the right school, got the right job, married the right man, bought the right house; all in preparation for becoming a mother.

In November of 2001, it seemed that my dream was finally going to come true. My pregnancy was uneventful. The nursery was finished and all that remained was to bring home the baby. On November 15th, almost 39 weeks pregnant, as I sat in a meeting at work, I realized I had not felt the baby move in some time. At the hospital, the nurse could not locate a heartbeat. The doctor using an ultrasound found pulsing at the heart and made the decision to deliver by crash cesarean section. As I was being put under, all I could think was "God, please don't take my baby."

He was 8lbs 5oz and 21 ½ inches long. A full head of dark hair crowned a face everyone said was too pretty to be a boy's. His lips and hands were identical to his father's, however, his ears and nose were all mine. Even though the doctor delivered him in less than 10 minutes and the neonatologist and team worked on him for over 20 minutes, that was the last time my son would be considered a human being.

A baby born at 20 weeks gestation with absolutely no chance of survival, yet whose heart is beating at birth for just moments, is considered a baby. Our state acknowledges that a child was born and died. The parents are given a certificate of live birth and a death certificate. They are granted the closure that comes with the acknowledgement of a life lost.

My son born at near term who likely would have lived a long productive life, but for a cord accident, is acknowledged not at all. I was not a mother, my husband not a father. We grieved and still grieve for the loss of our hopes, dreams, future.

I've since delivered two additional children. It amazed me after my older daughter's birth that my 6lb 6oz baby girl, born at 37 weeks gestation was unquestionably a human child, where my son was not given the same consideration.

A certificate of birth resulting in stillbirth will not bring my son back. It will not make me grieve less. Nor will it heal the hole that was left when my son died. He did die, by the way. Whether it occurs in a mother's womb or in the open air, when a heart stops beating, a life is lost. What the certificate would do is validate for the world to see, that my son did live. It would show that he had a name, Matthew Jacob Foner and a birthday.

To many, a certificate would seem such an insignificant thing. I would suggest they never heard a heartbeat strong and clear, felt movements that would take their breath away, loved a being with every ounce of their soul only to have it taken away from them and then be told that it never was.

Kara Foner
11953 Kerry St NW
Coon Rapids, MN 55433
763-422-1603
dkfoner@hotmail.com

Subject: Re: Missing Angel Bill

Date: Tuesday, March 22, 2005 3:46 PM

From: Candy <candy@missinggrace.org>

To: "Mikyska, Jeana M" <Jeana.Mikyska@allina.com>

On 3/22/05 2:47 PM, "Mikyska, Jeana M" <Jeana.Mikyska@allina.com> wrote:

Our son's name is Dalton Joseph Mikyska, born 11/14/02 and he was born stillborn at 38 1/2 weeks gestational age. I went through 24 hours of labor to bring an angel into the world. This is important as even though he was born stillborn his birth should still be recognized as well as his death. Even though the date is the same. They are special babies in their own way even if they didn't get to take a breath at all.

We didn't receive a birth certificate at our sons birth. Yes it does make you feel like your child was never "born" being you don't receive one. We have a curio cabinet in our home dedicated to our son, Dalton, with all the gifts we received at his funeral and the box of cards we received. A picture album is in there and a fake birth certificate the hospital gave to us. Looks tacky - a nice formal one would be a nice touch for his memory. I would like to receive one and sure most parents in this situation would agree.

I won't be able to attend as I have to work - but wishing you all lots of luck and prayer.

Jeana Mikyska
16120 Auburn Rd
Grasston MN 55030
320-679-2698
jjm041301@yahoo.com

Subject: Missing Angel Bill -- Testimonial

Date: Tuesday, March 22, 2005 3:59 PM

From: Candy <candy@missinggrace.org>

Date: Mon, 21 Mar 2005 10:43:41 -0500
To: rep.karen.klinzing@house.mn
From: Tim Nelson <tn@aplacetoremember.com>
Subject: Missing Angel Bill -- Testimonial

Representative Klinzing,

As both the father of a full term stillborn child and owner of a company that provides resources to families following a stillbirth, I am keenly aware of the importance of issuing a birth certificate to these grieving parents. It is both cruel and harmful to the healing process to say to a parent who has just held their baby in their arms that this child technically never existed.

Even 21 years later I vividly remember the feeling of being punched in the stomach when the nurse informed me that we would receive no birth certificate but could I please sign the certificate of death. Thank you for your support of this important bill.

Tim Nelson
Publisher
A Place To Remember

--

Tim Nelson
deRuyter Nelson / A Place To Remember
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651-645-7045; FAX 651-645-4780
tnelson@deRuyterNelson.com / tn@APlaceToRemember.com

HOME:
Nelson
7203 Sherwood Echo
Woodbury MN 55125

March 22, 2005

To whom it may concern:

I am writing to voice my support for the Minnesota Stillbirth Certificate/Missing Angels bill. As a parent of a stillborn child I am currently given a Fetal death certificate stating that my child has died. According to how the law currently reads my doctor is required to record the death, but not the birth of my child. How can there be death if there is no birth? If you ask my doctor she could tell you when my son was born, how much he weighed, how long he was, and what his name was. Could the state? If they looked at the records would they even know if I had a boy or girl? As a mother I could tell you more about my son, but I am just asking that the state recognize my child had a name. That his life is worth recording, not just his death.

Thank you for your support,



Nicole Riley
10410 34th Place Ne
St. Michael, MN 55376
(763) 497-2088
forever5babies@yahoo.com

Subject: Testimonial on stillbirth for 3-23-05 hearing

Date: Tuesday, March 22, 2005 7:45 AM

From: Candy <candy@missinggrace.org>

On 3/21/05 10:01 AM, "Linda McComb" <adnil1mom@msn.com> wrote:

Hi, my name is Linda McComb, mother of five children. Unfortunately my last child, Jamie Sue is not with us because she never made it to the finish line of live birth on December 3, 2002. She grew inside her mommy like other healthy babies. I had a normal pregnancy even for a 39 year old mom. Jamie had 3 brothers and 1 big sister awaiting her at home. But she never came home physically only in the hearts and minds and tears of her family. Ask any mom how it feels to carry a baby for nine months inside, prepare for their arrival and then bring them home at last. It is an awesome feeling, more fulfilling than anything else a woman can experience. But ask a mom of a stillborn child how she feels, she will tell you she feels cheated, incomplete and lost somewhere on the highway of life. The "world" on the other hand, tells her to morn abit and then go back to life and "get over it". And because of the fact that there is no birth-certificate (resulting in a stillbirth even) to show that the child ever even existed, well, that is cruel and heartless. People need their birth certificates for various things in life, even though it is only a piece of paper, it is however important to an individual. Like wise for the parents of a stillborn child, that "piece of paper" is very important in different ways. It acknowledges for the parents that their baby was born and was a person of value. Words cannot describe how meaningfull it would be to have a certified piece of paper from the state of Minnesota stating that I did give birth to a daughter, Jamie Sue on December 3, 2002 and that she did matter.

Thank you.

Sincerely,

*Linda S. McComb
13681 93rd st.
Otsego, MN. 55330
763 441-6621
adnil1mom@msn.com*

Subject: Missing Angels Bill Our Story

Date: Monday, March 21, 2005 6:10 AM

From: Michael Lemmer <mlemmer@newulmtel.net>

To: <candy@missinggrace.org>

arch 21, 2005 Minnesota Missing Angels Bill Our Testimonial~ In Remembrance Of Our Son, Aidan

We are Michael and Melanie Lemmer, parents to Aidan Lee. My husband and I tried to get pregnant for over a year and conceived him on my 25th birthday in 2001. We had planned on him being our last and littlest son. We cherished his pregnancy and the schedules we knew he followed. The little things matter so much now, as those pregnancy memories are all we have aside from the memory of saying goodbye.

We had the same exact pregnancy as we did with Aidan's two big brothers. At the same point each time, 3 weeks before I would have them, my blood pressure would rise. I had had preeclampsia with Anson (1996) and he was born at 36 weeks weighing 6lbs6oz. Alex (1998) was next with hypertension, but no protein, he was born at the same point, weighing 7lbs3oz. We had seen a midwife during Aidan's pregnancy until that point, then we were referred to a new doctor at the medical center because of my blood pressure. We have since learned she'd gotten her license in July 2001. Had we known this beforehand, things would have been so different.

We trusted our hospital's care prior to his birth. Hutchinson is not that small of a town. They were very into following through, or so we thought. I was hospitalized twice with migraines that were horrible, elevated blood pressure and trace protein during the last two weeks. Aidan looked "fine" on their monitors. We were seen every day except Sunday and had stress tests, nonstress tests and ultrasounds right up until Friday before his birth but few lab tests were done. I was scheduled to be induced Monday Nov. 26th, because it was "getting risky" with my blood pressure. I had gone into labor originally on the Monday before, but she put me on Brethine to stop it for that last week. I was over two cm dilated & ready. I took the last one Saturday afternoon, early Sunday morning, November 25th, 2001~ or lives changed forever.

Aidan went into distress within a short time after our arrival. Things went fast when they ordered an emergency c-section to deliver him because he was in trouble. The last thing I was told by the doctor was "don't worry soon you'll be holding your baby". She never said he would not be alive. By the time I got into the OR I was in excruciating pain. I began to hallucinate and held a conversation with my deceased grandfather, it turned out to be the nurse who held my hand as I passed out waiting for the surgeon...

The surgeon came from church, the anesthesiologist from home. This is an emergency medicine hospital, mind you, and they were not *on site*. I waited over an hour for an emergency c-section. The incision was made at 10:23am They'd ordered it at 9:17am. The time made all the difference.

Aidan was born not breathing and they were unable to resuscitate him. He weighed 6lbs1oz and was perfectly healthy from head to toe with my husband's big brown eyes and long lashes, just like both of his big brothers and my tiny nose and chin.

They prepared my husband for my death as I had lost over half of my body's blood volume. I had contracted so hard I had a uterine rupture clear down the top of the dome of my uterus. It tore to my uterine artery- which goes to my heart. I was in ICU and very drugged when I came to, the same doctor who was "taking care" of us, said "your baby is dead." That day changed us forever.

We had him baptized and took only a couple photos of him, actually a nurse did (she had a stillborn baby 30+ yrs ago & they never let her see him/her.) She said they were for when we were ready and now do I ever wish I had a million more!!!

Just like we had with our other two children, our live babies, we held him and kissed him and told him we loved him. But then we had to say goodbye- give our baby back and go home to an empty nursery. We went home to his nursery, beautifully decorated for him by his big brothers with a Welcome Home sign in crayon- without the baby boy we'd prepared for. We came home with his hat, blanket and Death Certificate.

Aidan's birthday in heaven is November 25th. It was hard on all of us, but we *celebrate* his life. We all release balloons at sunset and the boys were told their words would stay with the balloons all the way to Aidan... the words his brothers say that day ring in my ears and remind me how very missed this precious little boy is to us all.

Weeks later we received his autopsy report and the answers to why our perfectly healthy baby died. We had not received Birth Certificate- only a Death Certificate. I gave birth to this child- our son and that recognition is very important to me and my family. I endured labor and a horrific delivery- but I Gave Birth even though he died.

The Missing Angels Bill is very important to our family, and many others like it. Please think of us and remember Our children are loved and out of respect should count too!

Sincerely, The Lemmer Family

Melanie, Michael, Anson, Alex and Avery Lemmer

1427 Hauenstein Drive New Ulm, MN 56073 (507) 359-2380

Missing Angel Bill 2005

My name is Sherokee Ilse. My first son's name is Brennan William Ilse, he was stillborn on Nov. 2, 1981 and profoundly changing my life forever.

After laboring for hours and naturally delivering him, I thought it morbid to take pictures, no family members saw him, and my husband David and I left Fairview Riverside hospital in Mpls with no birth certificate no crib card, no foot prints, no mementos, no literature ---leaving that hospital with empty arms and broken hearts was one of the toughest things we have ever done in our lives.

Our fullterm son, 6 ½ pounds with brown hair, pursed lips, beautiful body with tightly closed eyes, was born without life, yet he had lived within me for 40 weeks, within our hearts for years and his future was mapped out like only prospective parents can understand. Little did I know that after that momentous event, my life would never even be close to the same.

The terrible decisions we had made not to introduce him to family, not to spend more time with him, not to take pictures, and not to say hello before we rushed to say goodbye haunted us for years. The staff was kind but rather clueless about how to really help us deal with each of these significant decisions. Tears were shared with us, but that was far from enough. It was a shocking, soul rocking thing to realize how the death of such a tiny baby could knock us off our feet and impact every moment of our day and night.

As a result of this I changed my career, my direction and my mission. I wrote a book, entitled, Empty Arms, and gave it away freely to hospitals and doctors suggesting that families deserved more guidance than we had received, which was standard procedure at that time. Physicians, nurses, social workers and bereaved parents started calling for advice and from this others joined me in the creation of a national nonprofit organization dedicated to helping families and caregivers. I don't have time to tell you all the wonderful changes we were able to institute throughout Minnesota and the country – through workshops and inservices, writing literature and articles, marching with baby blankets down the Capitol Mall in Washington, DC to celebrate and honor babies our babies with President Reagan's National Proclamation of October as Pregnancy and Infant Loss Month in our hands. Many good things have happened, yet there are many pieces missing – one being what we are talking about today – a birth certificate for these anguishing families.

Back to Brennan--the one and only thing we did receive was a fetal death certificate. How odd, a death certificate but no birth certificate. It has troubled me for 23 years. In fact, I wrote to a group in Colorado to receive just such a memento, knowing full well it was not official, Not just my family, but thousands and thousands of MN and US families have not received an official acknowledgment from the state of their babies'

births. This must change which is why I submit to you this letter and testimonial.

At this time, 11 states including Arizona the first, Massachusetts, Ohio, New Jersey, Wisconsin, Indiana, Maryland and many others have changed that.

While Minnesota was a key state through our organization to change so many wonderful things in this country, we have not been able to make this simple, yet important certificate of stillbirth a reality. Which is why I am asking you today – to open your hearts to these families and pass this simple bill giving them the opportunity to receive an acknowledgment and an important memento of their beloved baby's birth at the time or even like in my case decades later. All we have are memories, no first coos, or first steps, or whispered words of, "I love you mommy. I love you daddy." This small request for a certificate of stillbirth can't replace those life moments, but they can give a families a little more peace and comfort... a chance to show their family and friends, who often act like nothing happened, that a baby, a beloved daughter or son was indeed born, has died and will be forever loved and remembered.

Thank you. This means the world to the parents I am representing.

The moms and dads of Minnesota will send you their prayers of thanks, even if they never write you a letter or call you personally- they will be grateful. This is your chance to make a serious difference in their lives. We're counting on you. Please pass this bipartisan bill.

Thank you.

Sherokee Ilse

3630 Eileen St

Maple Plain, MN 55359

952-476-2804

(<http://www.missingangelsbill.org/#stchart>) for more information.

Subject: Certificate of Birt, Resulting in Stillbirth

Date: Tuesday, March 22, 2005 4:31 PM

From: Ed and Lori Boettcher <loed@runestone.net>

To: Candy McVicar <mcvicar@mninter.net>

Issuing Angel Bill 2005

My name is Lori Boettcher. My one and only daughter's name is Brielle Anne Boettcher who was born still on February 19, 2004. She weighed 6lb 14oz and was absolutely perfect. Her life inside my womb and death just hours before her birth has taken me to places that are difficult to explain. She has taken me to my knees and given me the strength to rise again.

The wounds of Brielle's passing have not yet healed, and I've faced the fact that there will always be a deep scar bearing her name.

February 19, 2004 was a day my husband and I had been looking forward to for 14 years. . . I was in labor with our first child. At 2:30 am we arrived at the hospital and were checked by the nurse and doctor. Our baby was full term, and everything was on track. Our doctor said we'd have a baby by noon. At noon, our world came crashing down. Instead of the arrival of the baby we'd waited so long for, we were told our dear little daughter Brielle was "gone". After 9.5 hours of monitored labor in the hospital, she was "gone"! How could that be? I think we put ourselves in another world to get through the rest of labor, and our angel Brielle was born through natural child birth 9.5 hours after her death. That was the first tragedy.

Within a week, our family met at the local funeral home to plan Brielle's funeral. We chose a casket, selected service folders, and wrote a check out for death and birth certificates. We buried our little girl on February 26th , 2004. That's the second tragedy.

The weeks, months, and year that followed were absolutely unbearable. My husband and I felt things that we are still unable to describe. To say, "You'd have to be there" is an understatement. The baby we'd planned for, cared for, and labored with for over 30 hours was gone. The doctor said if she'd been delivered via c-section at 2:30 am, she'd be here with us today. Not something either my husband or I really cared to hear at the time.

Approximately one month after Brielle's death, we were contacted by Colleen who works at our local funeral home. We weren't prepared for the news she had for us. She explained that in the past month she had been busy trying to figure out what was holding up Brielle's death and birth certificates. She had first contacted our local county office and was told to contact state offices. At the state level, she was told to talk with the county where the child was born. So, for a month, she made phone calls, waited for returned calls, and basically got the run around. No one seemed to be able to tell her what the hold up was with the death and birth certificates. Then, someone finally told her. There would be no birth certificate because Brielle wasn't born in the eyes of the state of Minnesota. Wasn't born?! I wish the State of Minnesota could have been in the labor and delivery room. There was definitely a birth! I wish the State of Minnesota would have been able to feel Brielle's kicks, see her grow inside my womb, and listen to her heartbeat during the 39 weeks we carried her. In the end, the people from the funeral home told us we would be receiving a death certificate in the mail. A death certificate? How can there be a death certificate if there isn't a birth certificate? My husband and I were devastated.

We were so hurt and honestly angry that we chose not to send money to the State for an official death certificate. Instead we have a copy of an unofficial death certificate to go along with the unofficial birth certificate given to us by our friends. We were and continue to be extremely disappointed that our daughter's birth is not recognized by our state.

How can the birth of our little girl not be acknowledged yet Scott Peterson can be charged and found guilty of TWO murders - one his wife and one his unborn child? Under Minnesota Statute 609.2661 if someone is found guilty of causing the death of an unborn child while committing an intentional act, they must be sentenced to prison for life. If a person is found guilty of the unintentional death of an unborn child, Minnesota Statute 609.2662 states that the person can be imprisoned for up to 40 years. According to case history pertaining to these statutes, it does not matter how old the unborn child is and it does not matter if the defendant knew the female was pregnant. I wonder, if the unborn child in

these cases are so important - which I believe they should be - why is our daughter's birth not even acknowledged by the state of Minnesota? Why isn't our daughter important to Minnesota?

Under Minnesota Statute section 145.1621, it is a misdemeanor to fail to properly dispose of a human fetus. The purpose of the statute is to "protect the public health and welfare by providing for the DIGNIFIED and sanitary disposition of the remains. ..." In other words, the legislature has already decided it is necessary to treat unborn children with some measure of dignity and respect. It would seem consistent with the given statutes that when an unborn child dies whether months, days, or hours before being born, we recognize that child as legitimate. For me, legitimacy includes the recognition of birth via a certificate from the State of Minnesota.

My husband and I continue to grieve the loss of our sweet daughter Brielle. We continue to be terribly disappointed that we never received a birth certificate for our daughter. A certificate of birth resulting in stillbirth will not bring Brielle back, but it will acknowledge that Brielle was born into this world. It will acknowledge that she had parents who cared for her and did give birth to her. It may also provide a way to track the number of stillbirths and result in further research in this area. Finally, a certificate of birth resulting in stillbirth will help take the salt out of an already deep wound.

Thank You.

Lori Boettcher

45356 140th Street

Donnelly, MN 56235

J-795-2919

Certificate of Birth Resulting in Stillbirth

Tuesday, March 22, 2005

When my daughter Laura was 19 months old, she learned that she was going to become a big sister. She was ecstatic, and promptly learned to sing "Twinkle, Twinkle, Little Star" for the baby. As my belly grew larger, Laura would follow me around singing "Twinkle" to the baby. The pregnancy went well, but I started having frequent contractions too early. I was put on bed rest, as I had been when I carried Laura. We did not mind the inconvenience because we would do whatever it took to get our baby here safely. Once I got closer to my due date, I was taken off bed rest. I was a kick-count expert by this time, and very aware of my baby's schedule.

On Thursday, October 1, 1998 I felt restless and could not go to sleep. The baby was very active from 10PM-12AM. Eventually, Baby settled down and I slept. When I awoke the next morning, I called my mom and told her that "today is the day!" She came over to care for Laura, and we did laundry together. I washed the outfit I wanted to bring my baby home in. It was not girlish or boyish; we did not know whether we would bring home a brother or sister for Laura. It was a busy day, and I talked to my baby a lot. I remember that Baby was quiet, but I figured that is normal because babies are stressed during labor which probably quiets them down. That evening, we tucked Laura in to bed before we headed to the hospital. As I kissed her, I whispered, "I love you Laura! We are going to the hospital. Your life is about to change forever!"

The nurse at North Memorial could not find our baby's heart beat, because our baby was gone. She called my midwife, who ordered an ultrasound. A resident brought it the machine, and the ultrasound showed our baby's rib cage. It looked hollow; the heart was not beating. I thought I saw umbilical cord wrapped around the baby's neck. It was 1AM by this time, the midwife sent me home for the night. Dad and Mom were waiting at our house. One of the most difficult moments of losing my baby was facing my dad, seeing his anguish, hearing him sob as he held me. I realized the depth of his love for me, and it was overwhelming.

The next morning was worse, much worse, because Mark and I had the responsibility of telling our dear Laura that she was not going to be a big sister. Mark gathered Laura up in his arms, and warned her that he had some very sad news. "Our baby has died, Sweetie." She burst into tears. As Mark started cooking breakfast, I turned on "Teletubbies" for Laura. She saw the happy baby in the sun, the one who coos and laughs. Laura wondered, "Why can't we have that baby, Mommy?" Later, she asked me whether she had killed the baby, if

she had squished the baby in my tummy. We took her to play with her cousins at my in-laws while we drove back to North Memorial to deliver our baby.

We had a son. His cord was knotted and wrapped once around his neck. I prayed, "Breathe, just breathe," but he did not. Otherwise, he was perfect. We were devastated. It was so unfair that Mark would not get to raise his first son. We named our little man Erik Pearce. After his bath, we dressed him and told our families that they could come meet Erik. Laura came in the room first. I wanted to spare her the unbearable pain I was feeling. Laura climbed up on the bed, gazing in her brother's still face. Mark told her that this was her brother Erik, and that he had died. I asked if she wanted to touch him. She reached out her hand and caressed his cheek. I asked if she wanted to hold him, and put him in her arms. I asked if she wanted to say anything, she did not. I asked if she wanted to sing. Laura sang, "Twinkle, twinkle, little star, how I wonder where you are..."

Thank you for reading Erik's story. Please consider signing this bill. Know that it would bring comfort to all grieving parents if the birth of their precious stillborn child was acknowledged by a birth certificate. We were only offered a souvenir certificate, but it is very important to us. Recently, we moved into a new home. The first thing that went up on our wall was that framed copy of the souvenir certificate. Even now, I would treasure a true birth certificate. It would give me peace, because it would acknowledge the value of Erik's brief life.

Pam Smith

Email: mpsmitt@yahoo.com

5432 Crow Wing Hts. Ct.

Brainerd, MN 56401

218-824-0368



The Missing GRACE Organization

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Phone: 762-497-0709
www.MissingGRACE.org

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Charlie & Sue Olman

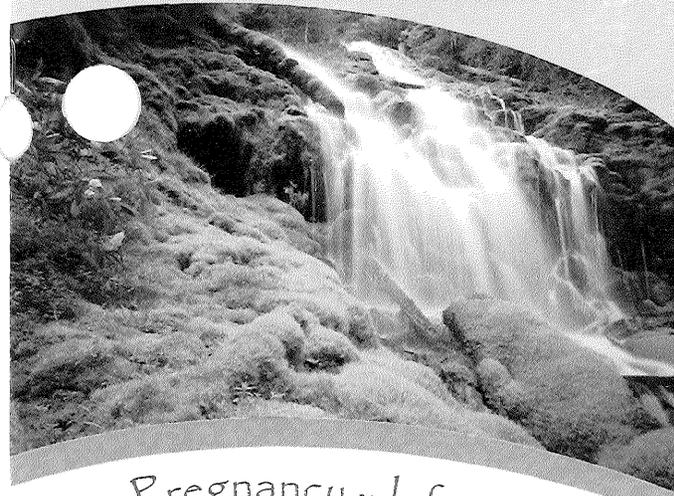
In Memory of Ray and Joan Olman

Shelly & Randy Davis

*In Memory of Grace McVicar
and all Heavenly Babies*

Lattie Ware

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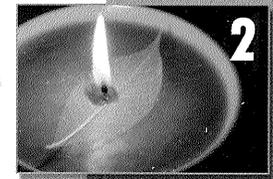
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A Weekend of Healing & Education

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The Missing GRACE Organization

The Missing GRACE Organization serves to help families on the journey through pregnancy and infant loss, infertility and adoption. We provide support and resources to aid individuals as they Grieve, Restore, Arise, Commemorate and Educate. Further, we commit to make available educational opportunities that will help bring about awareness and prevention of stillbirth.

The Missing GRACE Organization was formed by Candy McVicar after she and her husband, Steve, experienced the tragedy of stillbirth. Their daughter Grace was born December 20, 2001 and died due to a Velamentous Cord issue. Grace was perfectly healthy and her life could have been saved with proper medical management of the pregnancy. Candy committed herself to helping bring positive change to medical communities through stillbirth awareness and prevention. Bereaved parents from around the world in search of understanding and a non-judgmental source of support found Candy's personal website to be a tremendous resource and this led to the development of international and national relationships. The Missing GRACE Organization was initially formed to provide support to parents of stillborn babies. The organization has grown to include other life issues: loss from conception to the first year of life, infertility, and the trials and joys of adoption. In 2003, Candy organized the first annual G.R.A.C.E. Conference for parents to Grieve, Restore, Arise, Commemorate, and Educate. For more information visit www.MissingGRACE.org.

Conference Highlights

Five Tracks with Twenty-Six Educational Sessions:

Five Tracks including: Loss & Bereavement, Infertility, Adoption, Wellness, and Professional. Twenty-Six sessions to choose from, with more than forty speakers presenting. International and national highly acclaimed speakers: authors, physicians, clinicians, counselors and pastors, as well as bereaved, infertile and adoptive family panels.

Continuing Education Credits:

For healthcare professionals and caregivers. Social Work and Psychology Continuing Education Credits applied for. Social workers and psychologists may earn 1 CEU credit per class attended for a total of 3 CEUs on Saturday and 2 on Sunday. Nurses will earn 1.5 CEUs per class attended for a total of 4.5 CEUs on Saturday and 3 CEUs on Sunday. Attending all 5 classes in the Healthcare Professional Track will earn a total 7.5 CEUs.

SPA Services:

Grieving is hard work and it takes a toll on the whole body. Attendees will be able to treat themselves to some R & R with full body or chair massages and facials.

Consultation with a Doctor:

A great opportunity to have a private 10-15 minute free doctor consultation. Individuals and couples will be able to meet one on one with an RE, OB/GYN or Family Practice Physician to discuss questions about infertility, pregnancy and health issues.

Loss & Bereavement Track

Saturday Sessions

A1: Significance of Early Loss

A panel of parents will share their experience with first trimester loss, providing insight for friends and family. Diana Sundwall will provide encouragement and guidance.

A2: Place for GRACE

Candy and Stephen McVicar share their incredible story of how The Missing GRACE Organization was created through their experience with stillbirth, unplanned adoptions and infertility. Learn the keys to marriage survival after loss through the GRACE process (Grieve, Restore, Arise, Commemorate, Educate).

A3: The Gift of Time: Embracing the Brief Life of a Baby

Amy Kueblebeck, "Waiting with Gabriel" will offer comfort, practical suggestions and resources for parents, families and caregivers who have received a devastating prenatal diagnosis and have chosen to continue their pregnancies.

Infertility Track

B1: Honoring Your Waiting Process

Vera Snow teaches as your heart longs and waits, it can also bring comfort and peace as it actively reflects, discerns and distinguishes a delicate balance between what is *in* your control and what is *out* of your control.

B2: Infertility 101: For Friends and Family

Deborah Simmons, Ph.D. and Lisa Erickson, M.D. will teach the basics of infertility and offer the emotional tools needed to help support those trying to conceive. Panel will share about their journey and how friends and family offered constructive support.

B3: Medical Infertility 101

Dr. Bruce Campbell, a Reproductive Endocrinologist provides information on current technologies and approaches to achieving pregnancy, what treatments are successful for various health situations (PCOS, Endometriosis, and age related issues), and some of the known risks.

Adoption Track

C1: Options, So Many Options: Where to Start the Journey

Panel of Minnesota adoption agencies will present their resources and give practical information for starting the adoption process. Q & A to follow.

C2: Home study: Facts and Fiction

Class is designed to help alleviate stress and fears associated with completing a home study. Ann Sinnott will prepare you for when the social worker knocks on your door.

C3: Getting the Word Out

Kathy Quandt and Paul Krotz offer practical advice for reaching your community and beyond to market yourself as adoptive parents.

Wellness Track

D1: Holistic Approach to Obtain and Sustain a Healthy Pregnancy

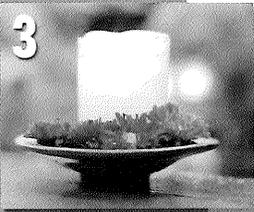
Mark Janikula, ND will teach you how to bring your body back into balance through a combination of homeopathic treatments including: diet, supplementation, homeopathy and herbal remedies.

D2: The Journey Toward Wholeness

Integrating traditional faith, the new science, spirituality and medicine, within a whole person model of a healthy Christian community. Session taught by Kenneth Bakken, M.D. and Rev. John Calbom.

D3: Prayer and Meditation

Learn practical ways to comfort the soul and find healing, peace and renewal in the light of God's love through prayer and meditation. Session taught by Kenneth Bakken, M.D. and Rev. John Calbom.



Saturday Sessions

continued

Professional Track

E1: Prevention of Stillbirth: A Comprehensive Review of Umbilical Cord Accidents (UCA)

Jason Collins, M.D. will teach you how to utilize current technology to determine which babies are at risk for cord accidents. Review extensive research dating back to the 1700's. Learn from the past to help prevent future stillbirth outcomes.

E2: Don't Forget the Fathers: Helping Grieving Men Find the Right Tools

Through his own experience, Tim Nelson offers healthcare Professionals tools to help care more effectively for grieving dads.

E3: Support for Parents at the Time of Loss and with Follow Up

Exceptional care for parents before, during and after the delivery surrounding a prenatal loss. Deborah Simmons, PhD. and Candy McVicar will help you match your care to the individual needs of each grieving family.

Sunday Sessions

Loss & Bereavement Track

A4(1): Let's Head to the Legislature

Would you like your state to recognize stillbirth? Richard Olson will teach you how to find out how easy it is and how you can be a part of the solution to fight stillbirth.

A4(2): Ask the Doctor

Q & A time with Dr. Collins for parents who have experienced a stillbirth.

A5: Daring to Love Again: Parenting a Subsequent Child

Sherokee Ilse "Empty Arms" gives insight through her experience on daring to love another baby and balancing grief while preparing for a new life. Dawn, the Founder of Nickolas' Gift, will share of her journey in having a child after her son Nickolas died of Potter's Syndrome.

Infertility Track

B4: Guy Talk: Infertility and Loss

An open forum session with John Healy PhD., Stephen McVicar and panel. Class is for men only, to discuss infertility and loss from a man's perspective. Topics include sexuality, marital challenges, finances, and employment.

B5: Infertility's Effect on Marriage

Mary Beohlke Psy.D.L.P. gives couples insights on how to cope with infertility and build a stronger marriage.

Adoption Track

C4: The Joys and Trials of Adoption

Panel of adoptive parents representing four different types of adoption journeys (foster care, international, domestic, multiple), share their stories of trial and triumph.

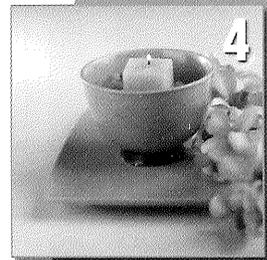
C5: Exploring Your Options: International or Domestic?

Richard Gibson will teach about various domestic and international adoption possibilities. Strengths and challenges are presented to assist in decision making.

Sunday Sessions: continued page 9

Conference Highlights

continued



Resource Tables:

More than 30 organizations will provide valuable resources and information for attendees. Complete your Table Card by visiting with all the exhibitors and you can be entered into our prize drawing. Represented exhibitors include: adoption agencies, spiritual and holistic health providers, book stores, bereavement support organizations, infertility support organizations and many more.

Silent Auction:

A growing list of fabulous items have been donated: hotel and vacation packages, spa services, jewelry, home and garden items, restaurant certificates, books, and artwork. Bidding begins at 10am on Saturday the 23rd and ends at 2:45pm on Sunday the 24th. Items will be awarded during the Closing Program which starts at 4:15pm on Sunday the 24th.

Grace Kids Program:

Provided onsite for children ages 6 weeks to 12 years old. Facilitated by licensed educators, social workers and counselors. The program is a fun-packed time of crafts, games and music activities. For those whom it is applicable, there will be therapeutic art and drama activities as well to help children with youth bereavement issues. The theme is CAMP GRACE and there will be a scavenger hunt, sleeping bag rest times, and camp-like indoor adventures throughout the weekend. Parents can check in on their kids at any time and will be happy to know that their children are located right down the hall next to where all the adult conference activities take place.

If your child or children are attending the GRACE Kids Program, please be sure to pack the following items in a backpack for each child:

- Child's medications, and note about any allergies
- For babies pack: bottles, milk or formula, nuk, extra diapers and wipes
- Sleeping bag (rolled up) & pillow
- Comfort toy or blanket that your child finds comforting
- Change of clothes (for those unexpected accidents)
- Comfortable play shoes
- Cooler with prepared meals, if you decide not to purchase from our menu

Conference Highlights: continued page 9

Saturday Dinner Banquet



Saturday Evening Dinner Banquet:

Keynote speaker, Amy Kuebelbeck, will share the message, "From Grief to Grace: A Journey of a Lifetime." There will be incredible music, dance and drama performances. Blue True Dream is back by popular demand, performed by Kirsten Frantzich and Clint Allen. We will close the evening with a time to commemorate and reflect with a memorial candle lighting and rose ceremony.

Registration Options

1. Online: www.MissingGRACE.org
 2. Mail To: The Missing GRACE Organization
P.O. Box 1625
Maple Grove, MN 55311-6625
 3. Walk-ins will be accepted (meals not guaranteed)
- I Want to Join the Missing GRACE Organization and Save on My Conference Registration Fee. (Missing GRACE Members receive a \$15 per family discount off the cost of registration). Annual membership is \$40.00 and includes: quarterly newsletter, GRACE tote bag filled with resources, and access to monthly teleconference calls with special guest speakers who present valuable information about pregnancy, infertility and adoption issues.
- I Want to Receive the GRACE Newsletter: Online By mail
- Please Add Me to the Missing GRACE Organization Email List. (Please Check All That Apply)
- I want to sponsor an individual or family to attend the conference. Please note the amount \$_____ in memory of _____
- I want to attend but need scholarship assistance.
Please contact Missing GRACE for an application. Scholarships are provided as donations are made.

I Would Like to Participate as a Volunteer for Missing GRACE Organization:
(Please also fill out the online volunteer form at www.MissingGRACE.org under Annual Conferences / 2005 / Volunteer Registration).

- In preparations before the GRACE Conference. At the GRACE Conference on April 23, 2005.
- At the GRACE Conference on April 24, 2005.

Baby Memorial:

I would like to purchase baby feet to have posted at the conference in memory of my baby. Each set of baby feet are \$10. _____ # of pink feet _____ # of blue feet _____ # of purple feet

The All Inclusive Registration Fee for Both Saturday, April 23rd and Sunday, April 24th Includes:
The opportunity to attend 5 sessions from a choice of 26 possible sessions, entrance to exhibition, Resource Table areas and Silent Auction, Saturday Opening Reception with appetizers, Saturday Evening Dinner Banquet, Sunday buffet lunch, beverage services throughout the conference, GRACE tote bag filled with resources, and free 5 minute chair massage ticket.

Payment:

Please make check or money order payable to: The Missing GRACE Organization. Credit card payments accepted with online registration.

Workshop Registration:

List the letter and number for the sessions you would like to attend. Indicate 1st and 2nd choices. Assignments are made in the order received. You will be notified of your sessions at registration. Sign up for all classes in a single track or mix and match to meet your individualized needs. Couples may each register for their own choice of sessions.

Saturday Evening Banquet Entree Choices Are:

- A: Burgundy Beef Tips over Linguini
B: Herb Baked Salmon with Champagne Sauce
C: Vegetarian Medley Stir Fry over Wild Rice Pilaf

All meals include coffee, hot or iced tea, garden salad, petite rolls, chef's choice of fruit and potato or rice, and two dessert selections.

Attendee Information:

Please print clearly. (Please use one registration sheet per household).

Name & Credentials:

(Print exactly as you want them to appear on your name tags, include profession; credentials, limit 3).

Your Name _____

Second Attendee's Name _____

Spouse/Significant other Relative Friend

Agency or Company Name _____

Address _____ Apt./Unit _____

City _____ State _____ Zip Code _____

Home Phone _____ Cell Phone _____

Email _____

GRACE Kids Program Registration:

Parents will be asked to fill out a detailed information sheet with information about any allergies, medications, special needs, etc. at registration. See brochure for items to pack for your child.

I will be enrolling one or more children in the GRACE Kids Program.

Name _____ Age _____

Meal Choices: Sat. Lunch A or B Sat. Dinner C or D Sun. Lunch A or B

Name _____ Age _____

Meal Choices: Sat. Lunch A or B Sat. Dinner C or D Sun. Lunch A or B

Name _____ Age _____

Meal Choices: Sat. Lunch A or B Sat. Dinner C or D Sun. Lunch A or B

Kids' Meal Choices Are:

Saturday Lunch A: Turkey and cheese sandwich on whole wheat bread

Lunch B: Cheese quesadilla with salsa

Dinner C: Baked chicken leg, rice, and green beans

Dinner D: Baked cheesy pasta with tomato sauce and green beans

Sunday Lunch A: Sliced baked chicken breast with BBQ sauce and baked jojo potatoes

Lunch B: All beef frank on a bun with baked jojo potatoes (seasoned and baked wedges)

All children's entree selections will be served with fruit, beverage, 1% milk or 100% juice, and a dessert. Children's meals are free from MSG, trans fats and peanuts.

Cancellation Policy:

Written cancellations received by April 13th will be refunded the full amount less \$40.00. After April 14th, 2005, no refunds will be issued. Substitutions can be made without penalty if the GRACE Organization is notified of the individual's name and registration information.

Select from 5 Tracks and 26 Sessions for Saturday, April 23, 2005 and Sunday, April 24, 2005

Session	Day / Time	Loss & Bereavement Track	Infertility Track	Adoption Track	Wellness Track	Professional Track	1st Choice	2nd Choice
1	Sat. 11:30 - 12:45	A1	B1	C1	D1	E1		
2	Sat. 1:15 - 2:30	A2	B2	C2	D2	E2		
3	Sat. 3:00 - 4:15	A3	B3	C3	D3	E3		
4	Sun. 1:15 - 2:30	A4(1) or A4(2)	B4	C4	D4	E4		
5	Sun. 2:45 - 4:00	A5	B5	C5	D5	E5		

Attendee (circle Saturday or Sunday for single days)	Advanced Registration Before 3/25/05	General Registration After 3/25/05	Sat. Eve. Banquet	Banquet Food Person #1	Banquet Food Person #2	Amount
<input type="checkbox"/> Individual Both Days All Inclusive	\$179	\$199	included	A B C	N/A	
<input type="checkbox"/> Individual One Day All Inclusive Sat. Sun.	\$125	\$137	included	A B C	N/A	
<input type="checkbox"/> Couple Both Days All Inclusive	\$300	\$330	included	A B C	A B C	
<input type="checkbox"/> Couple One Day All Inclusive	\$200	\$220	included	A B C	A B C	
<input type="checkbox"/> Professional Both Days	\$275	\$300	\$25	A B C	A B C	
<input type="checkbox"/> Professional One Day Sat. Sun.	\$175	\$200	\$25	A B C	A B C	
<input type="checkbox"/> Student Both Days (Must show proof of full time status)	\$133	\$154	\$25	A B C	A B C	
<input type="checkbox"/> Student One Day Sat. Sun.	\$90	\$100	\$25	A B C	A B C	
<input type="checkbox"/> Resource Table/Silent Auction Only One Day Pass	N/A	\$30/person	N/A	N/A	N/A	
<input type="checkbox"/> Saturday Evening Banquet Only	N/A	N/A	\$40/person	A B C	A B C	
GRACE Kids	Sat. Only	Sat. Lunch	Sat. Dinner	Sun. Only	Sun. Lunch	Both Days
<input type="checkbox"/> 6 weeks to 3 years old	\$50	\$6.95/meal	\$6.95/meal	\$35	\$6.95/meal	\$75
<input type="checkbox"/> 4 years to 12 years old	\$40	\$6.95/meal	\$6.95/meal	\$25	\$6.95/meal	\$55
<input type="checkbox"/> Discount for 3+ Children	\$112.50	\$6.95/meal	\$6.95/meal	\$78.75	\$6.95/meal	\$168.75

Become a New Member \$40 - Members can **SUBTRACT** \$15 from your Total

Add Cost for Baby Feet Memorials and Donations for Sponsorships

TOTAL AMOUNT DUE

Speakers

Kenneth Bakken, M.D., D.O., P.H. (D2, D3)

Is a nationally known and respected physician, ordained pastor and theologian, international public health scientist, and educator. He is the author of many critically acclaimed books, including: "The Call to Wholeness: Health as a Spiritual Journey", "The Journey Toward Wholeness: A Christ-Centered Approach to Health and Healing", as well as a wonderful video titled "The Heart of Healing Prayer." www.eskimo.com/~hvi/index.html

**Mary R. Boehlke Psy.D. L.P. (B5)**

Has worked for 15 years with individuals and couples dealing with infertility. She is currently in private practice in St. Louis Park, MN.

Bruce F. Campbell, M.D. (B3)

Had a private OB/GYN practice for many years in the Twin Cities before becoming a Reproductive Endocrinologist. He currently practices at the Center for Reproductive Medicine in Minneapolis, where he specializes in advanced infertility therapies. www.ivfmm.com

**Jason H. Collins, M.D., OB/GYN (E1, A4-2)**

Is founder of the Pregnancy Institute, Inc., a non-profit organization created to study normal pregnancies. It is designed to promote the likelihood of healthier pregnancies resulting in well-monitored, full-term live births. Dr. Collins started this institute and has devoted more than 20 years to the research of stillbirths. www.preginst.com

Lisa D. Erickson, M.D. (B2)

Graduated from her fellowship in Reproductive medicine from the Mayo Clinic in 1989, and was a staff physician until 1996. She then joined the Center for Reproductive Medicine in Minneapolis, where she specializes in IVF. She is a board-certified RE and a member of ASRM, ACOG and SART. www.wivfmm.com

**Karen Frazier, RN (E5)**

Is a bereaved parent who established the first bereavement support group in the Tampa Bay area for pregnancy loss. Her group AMEND has been in existence for over twenty-five years.

Douglas Huesby (D5)

Is the owner and CEO of Becker Furniture World. Doug was able to decrease the skyrocketing costs of Becker Furniture's healthcare premiums by getting rid of chemicals, cleaning the air and by offering healthy alternatives for meals. He created a pure line of personal care and home care products, and is the author of "Common Sense Wellness" and other health-related books. www.common Sense Wellness.com

**Sherokee Ruse (A5, E4)**

A bereaved parent, international speaker, author of "Empty Arms" and many other books. Her mission is to help improve the care families receive before and after the death of their child or loved one of any age. www.wintergreenpress.com

Mark Janikula, N.D. (D1)

A Naturopathic Doctor practicing in Stillwater, MN at the Natural Medicine Clinic. He uses safe and effective natural therapies to prevent and treat chronic disease. As an N.D., he bridges the gap between conventional and alternative medicine. www.thenaturalmedicineclinic.net

**Amy Kuebelbeck (A3 and Sat. Evening Keynote Speaker)**

The author of "Waiting with Gabriel: A Story of Cherishing a Baby's Brief Life." The book is a memoir about her infant son, who was diagnosed prenatally with an incurable heart defect. She is a former reporter and editor for The Associated Press in Minneapolis and has also written for newspapers including the Los Angeles Times and the Seattle Times.

Speakers: continued page 8

Speakers

Beth Ley, Ph.D. (D4)

Has her masters and doctorate degrees in nutrition. She has written almost 40 different books and booklets on nutrition and various supplements as well as nutrition and healing from a Biblical perspective. She also is a licensed minister under RAIN, of Brooklyn Park, MN.

**Tim Nelson (E2)**

Was a young father when his second child was unexpectedly stillborn. He wrote a booklet entitled, "A Father's Story." He co-owns A Place To Remember, which publishes and distributes books and other products for grieving families and their caregivers. He recently published his second book entitled, "A Guide For Fathers: When a baby dies." www.aplacetoremember.com

Richard K. Olsen (A4-1)

Founder and President of The National Stillbirth Society. Father to only daughter, Camille, who was stillborn at 40 weeks gestation. www.stillnomore.org

**Kathy Quandt & Paul Krotz (C-3)**

This Couple has one child and tried multiple fertility treatments without success. They have pursued adoption and creatively found ways to market themselves to a potential birthparent. www.hopetoadopt.org

Deborah Simmons, Ph.D. LMFT (B2, E3)

A marriage and family therapist specializing in the emotions of infertility and reproductive complications. Certified by the American Society for Reproductive Medicine, Dr. Simmons practices at Partners in Psychiatry and Psychology in Minnetonka.

**Vera Snow (B1)**

Author of, "When You Are Coping with Infertility," and creator of many support group materials. She writes, speaks and facilitates workshops on becoming intentional in letting go and finding balance when experiencing infertility.

Diana Hall (A1)

Diana Hall is the founder and Executive Director of Infants Remembered in Silence (IRIS), an organization dedicated to offering support, education and resources to parents, families, friends and professionals on the death of a child. www.irisremembers.com

**Additional Speakers:****Dawn Borchardt (A5)**

Founder and Director of Nickolas' Gift.

Rev. John Calborn (D2, D3)

Director, Trinity Retreat House.

Richard Gibson (C5)

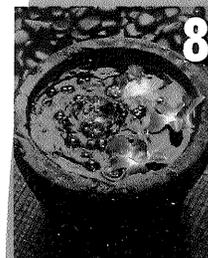
A Social Worker with Children's Home Society & Family Services.

John Healy, Ph.D. (B4)

A Psychotherapist specializing in counseling men facing assisted reproduction and loss.

Ann Sinnott (C2)

Director of Crossroads Adoption Services.



Sunday Sessions continued

Wellness Track

D4: Treating Stress Holistically

Learn the impact of stress on reproduction and what can be done through addressing the mind, body and spirit from a Christian Perspective. Holistic treatments to enhance sexual function and hormone balance will be taught by Beth Ley, Ph.D.

D5: Home Safe Home: How to Keep Your Home Safe from To

Learn about potential dangers present in objects and products used in daily living from Douglas Huseby. Practical measures are presented to protect your family's health and well-being.

Professional Track

E4: Giving Care, Taking Care: Support for the Helpers

Sherokee Ilse will teach how to provide passionate care to grieving families while ensuring that you take care of your own emotional and psychological needs, and "fill you own well."

E5: Building an Effective Support System for Bereaved Parents from the Hospital to the Home

Karen Frazier teaches you how to help staff find ways to be effective in providing consistent, supportive care, as well as support for bereaved parents in the years following the loss. Achieving connectivity and cohesiveness in providing optimal care for the patient who has experienced perinatal loss.

Conference Highlights continued

Your Tiny Prints Left an Eternal Impression on Our Hearts, Baby Feet Memorial:

At the GRACE Conference & Retreat we will be offering bereaved parents the opportunity to participate in our baby memorial. Parents will be able to write baby's name and birth date on pastel colors of pink, blue or purple cut-outs of baby feet. The purple feet are purposed for bereaved parents who did not even know the sex of their baby. There will be a table set aside for parents to decorate baby feet and all the baby feet will be on display for attendees to see at the conference. Parents are encouraged to bring a picture of their baby to attach to their baby feet. All the baby feet will go home with the parents to have as a keepsake.

2005 GRACE Conference & Retreat Schedule

Saturday April 23, 2005 at 10am the conference will start: On-site registration and pre-registration sign-in for the GRACE Conference & Retreat and for the GRACE Kids Program. Opening Reception starts - appetizers and beverages will be served. There will be time to visit with others, network, and meet with Resource Table representatives, get a chair massage in the Day Spa and place a bid at the Silent Auction.

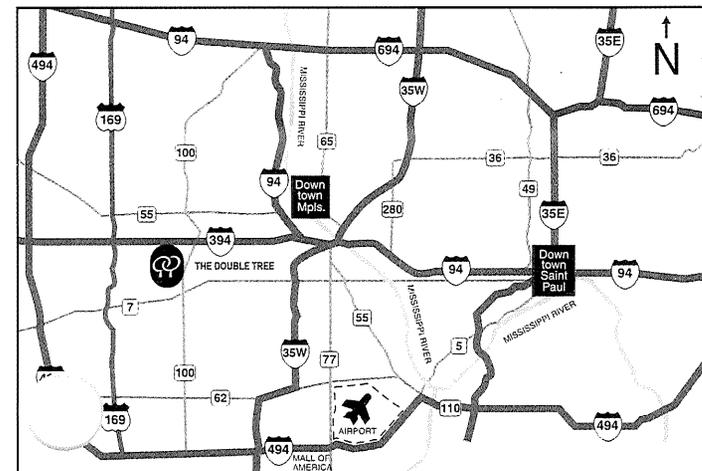
Saturday 10:00	11:30	12:45	1:15	2:30	3:00	4:15	6:15 - 9:15	
Sign in, Opening Reception	A1,B1,C1, D1,E1	Break	A2,B2,C2, D2,E2	Break	A3,B3,C3, D3,E3	Break	Dinner Banquet	
Sunday 9:00	10:00	10:00	11:30	1:15	2:30	2:45	4:00	4:15 - 4:45
GRACE Kids, Day Spa, Silent Auction	Resource Tables Open	Service	Lunch	A4(1 or 2), B4, C4, D4, E4	Break	A5, B5, C5, D5, E5	Break	Closing Program, Award of Silent Auction

Hotel Reservation and Directions

Reservations can be made by calling 1-800-222-TREE. Please reference the Missing GRACE Organization Conference or the Greater Minnesota Grace Organization (MGO). You can also book online by visiting www.mbletreeminneapolis.com. When booking a room, go to the Special Accounts column, enter MGO in the Group/Convention code in order to receive the Missing GRACE special discount rates. Room Information:

\$79.00 Standard Rooms, \$99.00 Executive Level, \$109.00 Suite Level (Children under 18 years old stay free)

Special rates are guaranteed until April 1, 2005. The GRACE conference rates do not reflect local taxes and fees, currently 6.5%.



From Minneapolis/St. Paul International Airport:

Depart Airport to west I-494, exit north on Highway 100, exit west on I-394, take first exit at Park Place Boulevard and go to stoplight. Turn left at stoplight and take overpass to hotel on right.

From I-35W Southbound/Northbound:

Exit I-94 west, then exit on I-394 west, take the Highway 100 south/Park Place Boulevard exit. Exit at Park Place Boulevard, turn left at stoplight and take overpass to hotel on right.

From I-94 Eastbound (from St. Cloud):

Take I-494 south, exit I-394 east, exit at Park Place Boulevard, turn right at stoplight, to hotel on right.

From I-94 Westbound (From St. Paul):

Exit I-394 west, take the Highway 100 south/Park Place Boulevard Exit, exit at Park Place Boulevard, turn left at stoplight and take overpass to hotel on right.

The Missing Angel Bill- Certificate of Birth for Stillborn Babies

The following 11 states offer a document, by legislation, that is a Certificate of Birth for parents of a stillborn child.

Arizona	LAW enacted 8-9-2001
Indiana	LAW enacted 7-1-2002
Louisiana	LAW enacted 8-15-2003
Maryland	LAW enacted 6-1-2003
Massachusetts	LAW enacted 8-10-2002
Missouri	LAW enacted 8-28-2004
New Jersey	LAW enacted 1-20-2004
South Carolina	LAW enacted 4-26-2004
Utah	LAW enacted 4-16-2002
Virginia	LAW enacted 7-1-2003
Wisconsin	LAW enacted 4-20-2004

Greetings Madam Chair, Health and Family Security Committee Members:

April 12, 2005

My name is Candy McVicar, I am a mother to my only child, Grace McVicar – a healthy beautiful and perfectly formed baby who would have turned 3 on December 20th had she been delivered in time. She was stillborn due to a cord issue and it was determined that an early delivery would have saved her life. After 22 hours of horrible labor I delivered Grace- This is our daughter and the family picture we treasure.

I felt a piece of my heart die when we lost our daughter. Time stood still and my world was changed forever and my course in life was radically altered. I experienced a grief that I could not have ever imagined. Sadly, I found out over time that I was not alone in having had a stillbirth. In fact there are 40,000 babies reported stillborn in the U.S. every year! This tragedy strikes everywhere in the world. It affects our neighbors, friends, family- it has even affected your fellow legislators. I share this experience of having had a stillborn baby with John Quincy Adams, John and Jackie Kennedy (whose daughter is buried with her parents and siblings), and Earnest and Pauline Hemmingway.

Childbirth is a profound passage in life. I chose to have a baby knowing there would be the pain and agony of giving birth but I felt as millions of women do- that it would be worth it to have the reward at the end. Birth is such an important event that we celebrate it every year in a ritual called the birthday. The birth of a stillborn is no different than the birth of a living baby other than the fact that it is a silent birth with no reward given for the hours of hard work.

When my husband and I went to purchase a coffin for our daughter, we had to fill out Grace's death certificate. I did not realize that I was only going to receive her death certificate and not her birth certificate. It added insult to injury when I was told that she was not considered born- just dead. How is that possible? How can a death certificate be given for someone that was considered not ever born? I received a pretend certificate from the hospital, but I have known in my heart it not the real thing, it doesn't truly acknowledge in a formal way that Grace was born. Even so, the symbolism is important to me and so I framed this pretend certificate in hopes to receive a real certificate of birth one day.

It is unfortunate that our hearing last week had to be cancelled, because we had 15 parents of stillborn babies from across the state of MN who had planned to be here to show their support of this invaluable bill for a Certificate of Birth Resulting in Stillbirth. They have asked me to share with you on their behalf how very important this is to them. I have provided each of you with a folder, with the testimonials and pictures from these parents and others who could not attend today.

I mentioned earlier that my course in life was radically altered. I would like to explain. I am now the Founder and Executive Dir. of an organization called The Missing GRACE Organization which I started to help assist bereaved families who needed support and help in the aftermath of a loss. GRACE is an acronym for Grieve, Restore, Arise, Commemorate & Educate. Last year in 2004, we assisted over 500 families in need of support and care. 100's of those whom we helped expressed their dismay and frustration that they did not receive a certificate of birth acknowledging their hard work of carrying and then delivering their baby.

We are asking you to please help us pass this bill and give MN parents the long overdue opportunity to receive a Certificate of Birth. Women deserve this! Parents deserve this. Other countries including: Canada, Norway, Ireland, Australia, and New Zealand currently issue certificates for stillborns. 11 other states in the U.S. currently offer a Certificate of Birth Resulting in Stillbirth also. Please help us add MN to the growing list of states who chose to do the right and just thing. As Martin Luther King Jr. said, "It is always the right time to do the right thing."

Thank you,



Candy McVicar
Founder and Executive Director, The Missing GRACE Organization
4943 Kaiser Ave. NE
Albertville, MN 55301

Phone: 763-497-0709 * Email: candy@missinggrace.org * Web Site: www.MissingGRACE.org

**Senate Counsel, Research,
and Fiscal Analysis**

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JO ANNE ZOFF SELLNER
DIRECTOR

Senate

State of Minnesota

S.F. No. 1274 - Flexible Health Benefits for Small Employers

Author: Senator Linda Scheid

Prepared by: Christopher B. Stang^{CS}, Senate Counsel (651/296-0539)

Date: April 5, 2005

Section 1 would permit group health plans issued to small employers to exclude or modify benefits otherwise mandated by state law.

Paragraph (a) permits insurers to issue flexible health plans if the following conditions are met:

- (1) the insurer accounts for less than ten percent of premiums in the Minnesota health insurance market;
- (2) the plan complies with chapter 62L, except as otherwise permitted by this section;
- (3) the plan must include consumer cost-sharing, such as deductibles and co-pays;
- (4) the plan must not exclude less healthy persons from group coverage and provide for them to be covered instead by the Minnesota Comprehensive Health Association;
- (5) the plan need not comply with the usual loss ratio requirements;
- (6) the plan may exclude or modify coverage for otherwise mandated benefits, except for maternity and other coverages required under federal law;
- (7) the plan may exclude or modify coverage for otherwise mandated coverage of care when provided by specific types of providers;

(8) the plan must be approved by the Commissioner of Commerce, who must not disapprove a plan because it omits a mandate; and

(9) prior to sale of the plan, the employer must be given a list of the mandates that are modified or excluded in the plan.

Paragraph (b) Provides that the definitions used in chapter 62L apply to this section, unless modified by this section.

Paragraph (c) Provides that it is legal under Minnesota law for an employer to provide to its employees a plan permitted by this section.

Section 2 makes the bill effective immediately.

CBS:cs

Senators Scheid, Moua, Sparks, LeClair and Kiscaden introduced--
S.F. No. 1274: Referred to the Committee on Commerce.

1 A bill for an act

2 relating to insurance; permitting flexible benefits
3 plans for small employer group health coverage;
4 proposing coding for new law in Minnesota Statutes,
5 chapter 62L.

6 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF MINNESOTA:

7 Section 1. [62L.056] [SMALL EMPLOYER FLEXIBLE BENEFITS
8 PLANS.]

9 (a) Notwithstanding any provision of this chapter, chapter
10 363A, or any other law to the contrary, a health carrier may
11 offer, sell, issue, and renew a health benefit plan that is a
12 flexible benefits plan under this section to a small employer if
13 the following requirements are satisfied:

14 (1) the health carrier is assessed less than ten percent of
15 the total amount assessed by the Minnesota Comprehensive Health
16 Association;

17 (2) the health benefit plan must be offered in compliance
18 with this chapter, except as otherwise permitted in this
19 section;

20 (3) the health benefit plan to be offered must be designed
21 to enable employers and covered persons to better manage costs
22 and coverage options through the use of co-pays, deductibles,
23 and other cost-sharing arrangements;

24 (4) the health benefit plan must be issued and administered
25 in compliance with sections 62E.141; 62L.03, subdivision 6; and

1 62L.12, subdivisions 3 and 4, relating to prohibitions against
2 enrolling in the Minnesota Comprehensive Health Association
3 persons eligible for employer group coverage;

4 (5) loss-ratio requirements do not apply to a health
5 benefit plan issued under this section;

6 (6) the health benefit plan may modify or exclude any or
7 all coverages of benefits that would otherwise be required by
8 law, except for maternity benefits and other benefits required
9 under federal law;

10 (7) the health benefit plan may modify or exclude any or
11 all coverages of services when provided by specific types of
12 health care providers otherwise required by law, except as
13 required by federal law;

14 (8) each health benefit plan must be approved by the
15 commissioner of commerce, but the commissioner may not
16 disapprove a plan on the grounds of a modification or exclusion
17 permitted under clause (6) or (7); and

18 (9) prior to sale of the health benefit plan, the small
19 employer must be given a written list of the coverages otherwise
20 required by law that are modified or excluded in the health
21 benefit plan. The list must include a description of each
22 coverage in the list and indicate whether the coverage is
23 modified or excluded. If a coverage is modified, the list must
24 describe the modification. The list may, but need not, also
25 list any or all coverages otherwise required by law that are
26 included in the health benefit plan and indicate that they are
27 included.

28 (b) The definitions in section 62L.02 apply to this section
29 as modified by this section.

30 (c) An employer may provide a health benefit plan permitted
31 under this section to its employees, the employees' dependents,
32 and other persons eligible for coverage under the employer's
33 plan, notwithstanding chapter 363A or any other law to the
34 contrary.

35 Sec. 2. [EFFECTIVE DATE.]

36 Section 1 is effective the day following final enactment.

1 Senator moves to amend S.F. No. 1274 as follows:

2 Page 2, line 9, after "law" insert ", and provided further
3 that maternity benefits may be excluded only if every employee
4 of the small employer approves the exclusion"



MINNESOTA

KEY VOTE

**Support Small Employer Alternative Health Insurance Benefit Plans
SF 1274 (Scheid, Moua, Sparks, LeClair, Kiscaden)**

- The bill allows small business to purchase a health insurance product that does not include the state mandated benefit set. The bill would give small business the flexibility to exempt all the mandated coverages they feel are unnecessary, similar to the flexibility that large business have under the federal ERISA law.
- In future years, coverages could be added or dropped.
- Currently, Minnesota has 62 mandated coverages, which is more than any other state in the country. The Alternative Health Insurance Benefit Plans could reduce premium by 20% or more.
- Since small employers would have the flexibility to pick and choose different mandated coverages upon renewal each year, certain specialty benefits geared toward a certain age or gender may not be necessary such as diabetic self-management and supplies, hearing aids and prostate screening.
- **A recent study by the Minnesota Department of Health and the University of Minnesota found that the uninsurance rate in Minnesota has increased. The results of the study show the uninsurance rate has increased from 5.4% in 2001 to 6.7% in 2004. Roughly 343,000 Minnesotans were uninsured in 2004. Small business needs relief from large premium increases and as much flexibility as possibly as they try to continue to offer critical health insurance benefits to their employees.**

Like large employers, small employers deserve the same flexibility to design benefit plans that meet the needs of their workforce. SF 1274 will give them that flexibility. The Small Employer Alternative Benefits Health Insurance Benefit Plan legislation is the number one priority for small business in the 2005 session and we urge your support.



April 12, 2005

Dear Members of the Health and Family Security Committee:

The National Alliance for the Mentally Ill of Minnesota is opposed to SF 1274, which would allow small employers to purchase health insurance plans that do not comply with the mandates required under Minnesota law. We believe this bill would make it more difficult for people to obtain mental health services.

The Minnesota Mental Health Action Group (MMHAG) which is chaired by Commissioner Goodno and Gary Cunningham, has stated that its vision is for "A comprehensive mental health system that is accessible and responsive to consumers; guided by clear goals and outcomes, and grounded in public/private partnerships." One of the goals is to develop a model benefit set for both public and private payers in order to prevent cost-shifting between payers. From the outset the MMHAG has focused on a public private partnership, understanding that mental illness should be treated as any other illness and that the private and public systems each have a role to play to **improve access to care and services**. Permitting small employers to exclude mental health benefits goes against the vision of MMHAG.

The President's New Freedom Commission indicated that in order for people with mental illness to participate in their communities, they need access to health care. President Bush said in his speech announcing the Commission (Albuquerque, New Mexico, April 29, 2002), "Our country must make a commitment: Americans with mental illness deserve our understanding, and they deserve excellent care. They deserve a health system that treats their illness with the same urgency as a physical illness." The final report issued by the Commission stated: *Insurance plans that place greater restrictions on treating mental illnesses than on other illnesses prevent some individuals from getting the care that would dramatically improve their lives. Mental health benefits have traditionally been more limited than other medical benefits. The Commission strongly supports the President's call for Federal legislation to provide full parity between insurance coverage for mental health care and for physical health care.*

SF 1274 would permit small employers to not cover state mandated services except for maternity benefits and any benefits required under federal law. Services required under current law (62L.05) include inpatient and outpatient services for the diagnosis and treatment of schizophrenia, bipolar disorder and various types of major affective disorder, delusional disorder and shared psychotic disorder, brief psychotic disorder and psychosis NOS (not otherwise specified), various autistic disorders, pervasive developmental disorder, and retts disorder. It also requires ten hours of outpatient mental health diagnosis and treatment for diagnoses not described above.

In a hearing on the house side it was stated that these new flexible plans would have to comply with federal law which does require mental health services. NAMI would like to clarify that **federal law does not require mental health treatment**. The Mental Health Parity Act that was signed into law in 1996 only requires parity in the application of aggregate lifetime and annual dollar limits. This means that if a health plan does not impose dollar limits on medical and surgical benefits, it cannot place limits on mental health benefits. Most importantly, the act does

Member



Community
Solutions Fund

NAMI-MN National Alliance for the Mentally Ill of Minnesota

800 Transfer Road, Suite 7A, St. Paul, MN 55114 Tel: 651-645-2948 or 1-888-473-0237 Fax 651-645-7379

not require health plans to include mental health benefits, parity only applies to those plans that offer mental health benefits. Additionally parity is not applied to small employers with fewer than 50 employees and any group health plan whose costs increase 1% due to parity. Plans are allowed to apply different cost-sharing requirements, and limits on visits or days of coverage.

Thus small businesses under SF 1274 would not be constrained in any way from excluding mental health coverage. We think this is wrong.

The business community must understand that saving a few dollars by not providing mental health benefits will cost them in the long run. The National Center for Health Care Purchasing recently released a monograph on this subject. Their report found that 34 million people between the ages of 18 and 64 have been diagnosed with a mental illness and for every one of them there are nearly two people whose condition has not been diagnosed. People who are not diagnosed or treated may not be able to thrive or succeed in the workplace and the employer may see increased absenteeism and turnover. Major depression is often associated with more annual sick days, higher rates of short-term disability and decreased productivity. In a study comparing depression treatment costs to lost productivity costs, 45 to 98% of treatment costs were offset by increased productivity.

It is truly time to recognize that our head is connected to the rest of our body. It is time to recognize that mental illnesses are biological brain disorders. Providing flexibility to small employers so that they no longer cover mental illness may save a very small amount of money, but the costs to the individual and their family will be great. Providing flexibility to small employers may save a dollar or two on their premiums, but will cost tax payers as private companies shift their employees with mental illness over to the public programs. NAMI adamantly opposes all efforts that will allow employers to exclude mental health benefits from their health care policies.

Sincerely,



Sue Abderholden
Executive Director

**Senate Counsel, Research,
and Fiscal Analysis**

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Senate
State of Minnesota

**S.F. No. 1934 - Region 10 Developmental Disabilities
Quality Assurance System**

Author: Senator Sheila Kiscaden

Prepared by: David Giel, Senate Research (296-7178)

Date: April 11, 2005

S.F. No. 1934 extends the Region 10 developmental disabilities quality assurance system in southeastern Minnesota for two more years, until June 30, 2009, and appropriates money to operate the system during the upcoming biennium.

Section 1 (256B.095) extends the Region 10 quality assurance system expiration date until June 30, 2009, from the June 30, 2007, date in current law.

Section 2 (256B.0951, subdivision 1) extends the Region 10 Quality Assurance Commission until June 30, 2009.

Section 3 (256B.0952, subdivision 5) allows quality assurance team members to receive a per diem regardless of whether they receive a salary or wages from an employer. Currently, team members who receive a salary or wages may not receive a per diem.

Section 4 (256B.0953, subdivision 1) reduces the minimum sample size for quality assurance team evaluations of a facility, program, or service to not less than two consumers from the current three. The requirement that the sample size must be at least five percent of consumers is unchanged.

Section 5 appropriates \$299,000 in fiscal year 2006 and \$450,000 in fiscal year 2007 to the Quality Assurance Commission.

DG:rd

Senators Kiscaden, Lourey, Sparks, Kierlin and Senjem introduced--
S.F. No. 1934: Referred to the Committee on Health and Family Security.

1 A bill for an act
2 relating to human services; modifying the quality
3 assurance system; appropriating money; amending
4 Minnesota Statutes 2004, sections 256B.095; 256B.0951,
5 subdivision 1; 256B.0952, subdivision 5; 256B.0953,
6 subdivision 1.

7 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF MINNESOTA:

8 Section 1. Minnesota Statutes 2004, section 256B.095, is
9 amended to read:

10 256B.095 [QUALITY ASSURANCE SYSTEM ESTABLISHED.]

11 (a) Effective July 1, 1998, a quality assurance system for
12 persons with developmental disabilities, which includes an
13 alternative quality assurance licensing system for programs, is
14 established in Dodge, Fillmore, Freeborn, Goodhue, Houston,
15 Mower, Olmsted, Rice, Steele, Wabasha, and Winona Counties for
16 the purpose of improving the quality of services provided to
17 persons with developmental disabilities. A county, at its
18 option, may choose to have all programs for persons with
19 developmental disabilities located within the county licensed
20 under chapter 245A using standards determined under the
21 alternative quality assurance licensing system or may continue
22 regulation of these programs under the licensing system operated
23 by the commissioner. The project expires on June 30, ~~2007~~ 2009.

24 (b) Effective July 1, 2003, a county not listed in
25 paragraph (a) may apply to participate in the quality assurance
26 system established under paragraph (a). The commission

1 established under section 256B.0951 may, at its option, allow
2 additional counties to participate in the system.

3 (c) Effective July 1, 2003, any county or group of counties
4 not listed in paragraph (a) may establish a quality assurance
5 system under this section. A new system established under this
6 section shall have the same rights and duties as the system
7 established under paragraph (a). A new system shall be governed
8 by a commission under section 256B.0951. The commissioner shall
9 appoint the initial commission members based on recommendations
10 from advocates, families, service providers, and counties in the
11 geographic area included in the new system. Counties that
12 choose to participate in a new system shall have the duties
13 assigned under section 256B.0952. The new system shall
14 establish a quality assurance process under section 256B.0953.
15 The provisions of section 256B.0954 shall apply to a new system
16 established under this paragraph. The commissioner shall
17 delegate authority to a new system established under this
18 paragraph according to section 256B.0955.

19 Sec. 2. Minnesota Statutes 2004, section 256B.0951,
20 subdivision 1, is amended to read:

21 Subdivision 1. [MEMBERSHIP.] The Quality Assurance
22 Commission is established. The commission consists of at least
23 14 but not more than 21 members as follows: at least three but
24 not more than five members representing advocacy organizations;
25 at least three but not more than five members representing
26 consumers, families, and their legal representatives; at least
27 three but not more than five members representing service
28 providers; at least three but not more than five members
29 representing counties; and the commissioner of human services or
30 the commissioner's designee. The first commission shall
31 establish membership guidelines for the transition and
32 recruitment of membership for the commission's ongoing
33 existence. Members of the commission who do not receive a
34 salary or wages from an employer for time spent on commission
35 duties may receive a per diem payment when performing commission
36 duties and functions. All members may be reimbursed for

1 expenses related to commission activities. Notwithstanding the
2 provisions of section 15.059, subdivision 5, the commission
3 expires on June 30, ~~2007~~ 2009.

4 Sec. 3. Minnesota Statutes 2004, section 256B.0952,
5 subdivision 5, is amended to read:

6 Subd. 5. [QUALITY ASSURANCE TEAMS.] Quality assurance
7 teams shall be comprised of county staff; providers; consumers,
8 families, and their legal representatives; members of advocacy
9 organizations; and other involved community members. Team
10 members must satisfactorily complete the training program
11 approved by the commission and must demonstrate
12 performance-based competency. Team members are not considered
13 to be county employees for purposes of workers' compensation,
14 unemployment insurance, or state retirement laws solely on the
15 basis of participation on a quality assurance team. The county
16 may pay a per diem to team members ~~who do not receive a salary~~
17 ~~or wages from an employer~~ for time spent on alternative quality
18 assurance process matters. All team members may be reimbursed
19 for expenses related to their participation in the alternative
20 process.

21 Sec. 4. Minnesota Statutes 2004, section 256B.0953,
22 subdivision 1, is amended to read:

23 Subdivision 1. [PROCESS COMPONENTS.] (a) The quality
24 assurance licensing process consists of an evaluation by a
25 quality assurance team of the facility, program, or service
26 according to outcome-based measurements. The process must
27 include an evaluation of a random sample of program consumers.
28 The sample must be representative of each service provided. The
29 sample size must be at least five percent of consumers but not
30 less than ~~three~~ two consumers.

31 (b) All consumers must be given the opportunity to be
32 included in the quality assurance process in addition to those
33 chosen for the random sample.

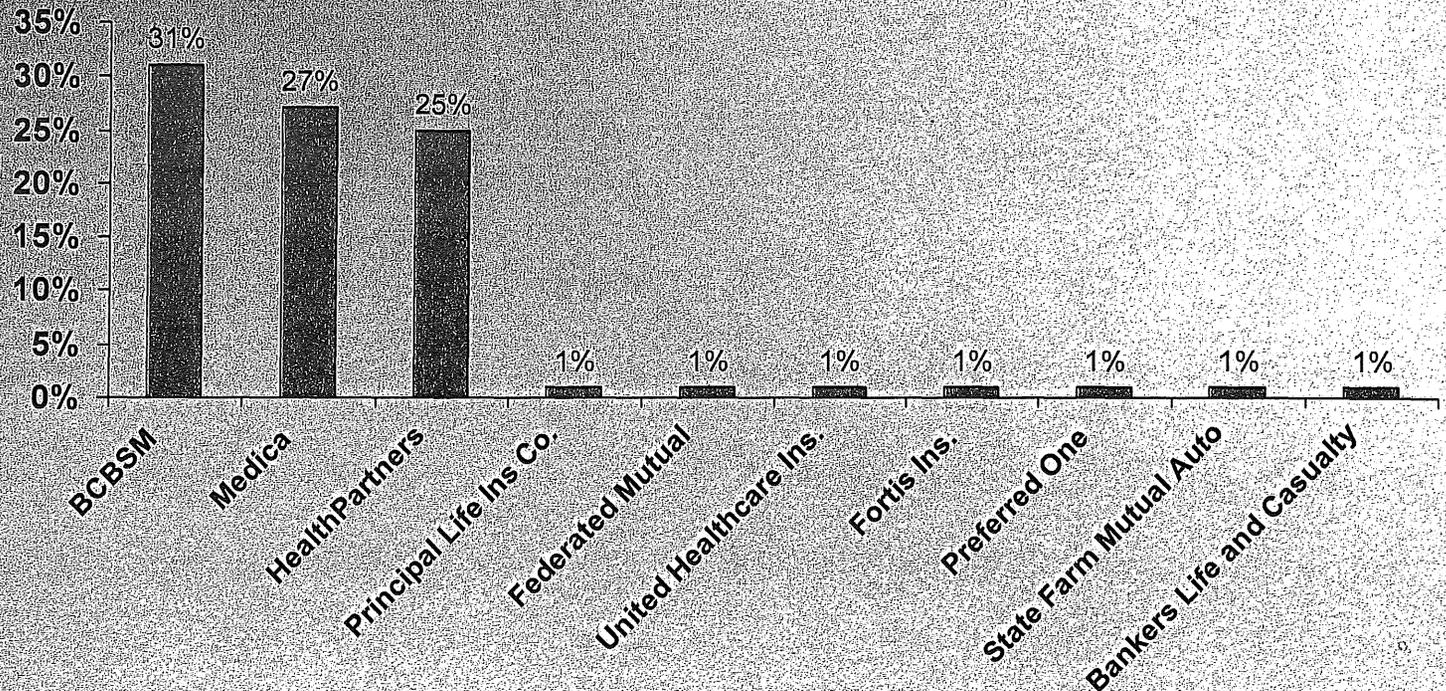
34 Sec. 5. [APPROPRIATIONS.]

35 \$299,000 in fiscal year 2006 and \$450,000 in fiscal year
36 2007 are appropriated from the general fund to the commissioner

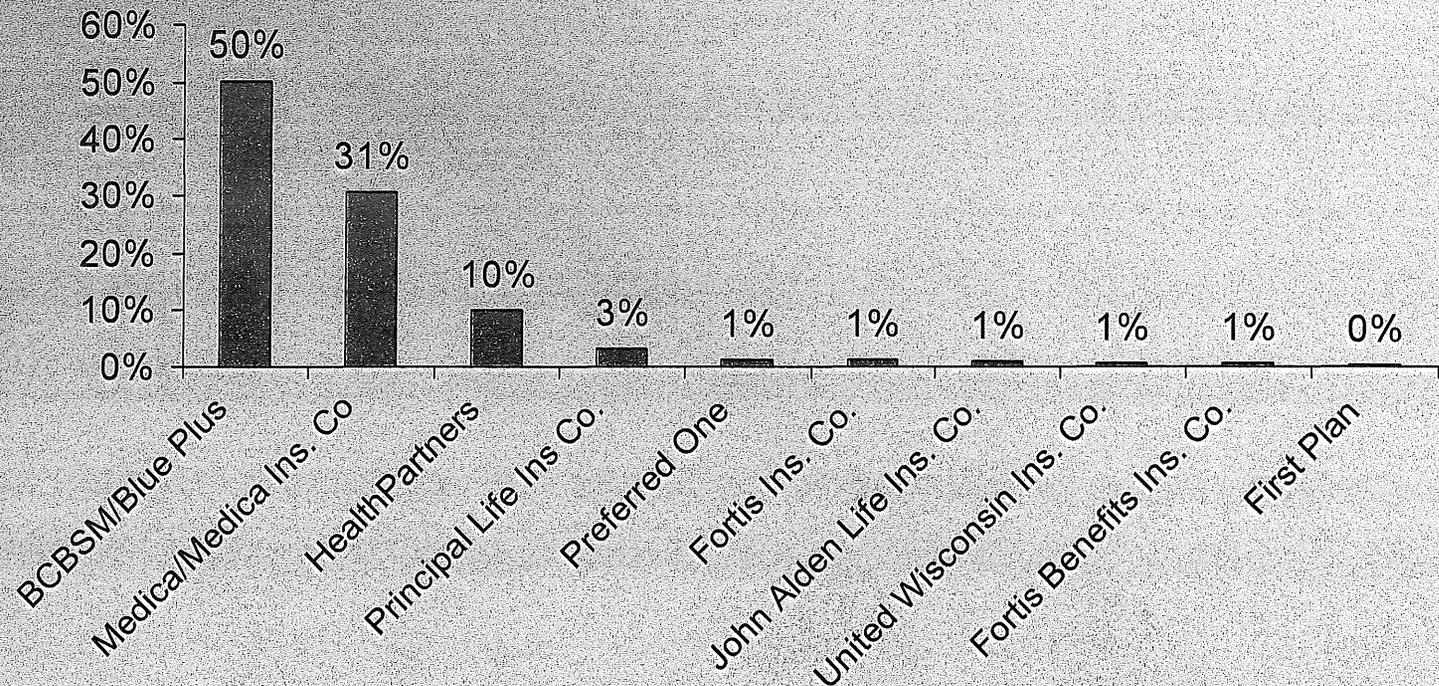
1 of human services for the Quality Assurance Commission under
2 Minnesota Statutes, section 256B.0951.

- 1 Senator moves to amend S.F. No. 1934 as follows:
- 2 Page 3, delete line 35
- 3 Page 3, line 36, delete "2007 are" and insert "\$151,000 in
4 fiscal year 2007 is"
- 5 Page 4, line 2, after the period, insert "This
6 appropriation shall become part of base level funding for the
7 commission for the biennium beginning July 1, 2007."

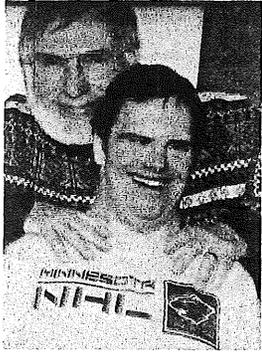
Minnesota's Commercial Health Insurance Market: 10 Largest Carriers by Market Share in 1999



Minnesota's Small Group Market: 10 Largest Carriers by Market Share in 1999



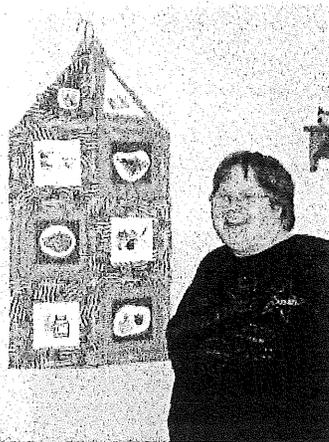
REGION 10 QUALITY ASSURANCE



John Gordon, parent, guardian, and member of the QA Commission:

Quality is all-important in our lives, for all of us. Some of us are able to manage the quality of our lives, what we do, what we buy, what we expect from the services we enjoy. Others need support in order to assure the quality in their lives, those added measures of satisfaction that say, "We have a good life, and we are pleased to contribute to the society that provides our quality of life."

My son, Andrew, is a man with Down Syndrome and VSD. He lives and works in a caring community. **VOICE** helps him express what is important in his life, what he needs and wants, and what his dreams are. He may not make it to his ideal dream (weatherman in Boston??), but he knows what makes him safe and happy. He works hard and is a contributing member of his community, and he appreciates the good life he leads. We assure that quality for him. Quality is not a luxury for us, and it's not a luxury for him. It's good money management. Quality makes the investment worthwhile!



Susan wrote: " The people who came to do my **VOICE** reviews listened to me. They found out what was important to me. I really like the shirt and wall hanging they made. Both were all about me. It is nice when people listen to me. I can make decisions for my self on many things. It is important speaking up for myself and giving others a chance to speak for themselves. " **Susan Huffman**

Kathy wrote: I am very impressed with the quality of the **VOICE** reviews. The teams that we have been involved with are thorough, thoughtful and knowledgeable about the things that are important to people with developmental disabilities They interviewed the staff people that Susan works with, her social skills counselor, her dad and I as well as Susan herself. With talking to all involved in Susan's day, they assessed the strengths and weaknesses of Susan's daily life. As we sat down to complete the exit review, I was amazed at the knowledge they were able to obtain. I think of that review as an umbrella giving me a wonderful overview of my daughter. Each person that Susan has contact with were like the spokes that give the umbrella it's shape. When they are all working for the same goal one has a strong umbrella protection. Our adults with developmental disabilities need to be a part of that strong umbrella with their voices heard. **Kathy Huffman**



My name is **John Jordan** and I am writing this in support of House file #1360. My son is a 34 year old man labeled Developmentally Disabled. He has multiple diagnoses of Autism, Epilepsy and Mental Retardation from infancy. He requires 24 hour awake care. He is intelligent and has many talents and skills. The Region 10 Quality Assurance Effort and **VOICE** reviews have been key elements in the evolution of his supports as an adult. Because of the new relationships and type of cooperation fostered in this person directed approach, he has been able to move from a highly structured and fairly restrictive setting (ICF/MR) into his own home in a town of his choice, where he hires his own staff. This has put him more and more in control of his own life, providing him with more options and opportunities to meet the ongoing challenges of his life. This alternative licensing/quality improvement system was essential to developing the new partnering and cooperation between him and the other key players in his life: family, county human services, DHS, service providers, advocates and his own board of Directors in his self-directed support corporation.



My son John Lufkin, 39, has been in the DD system for 21 years. He is a unique person with autistic-like behaviors , which now are recognized as a specific category, but years ago autism wasn't understood. When John entered a group home with one residential agency and a separate agency's day program, he was managed like other DD clients, but it didn't work! Autism was a behaviorally defined state and John acted out his frustrations. The 2 agencies needed to work together closely to co-ordinate his management, according to his needs and abilities. Finally, 1 day and 2 residential programs later, a Region 10 Quality Assurance review was available for John, in order for the current agencies to be licensed. What a relief!!! The QA team interviewed everyone associated with John. At the review, the QA team drew a picture of all of us, John in a boat, the rest of us as supports helping him row his boat, examining closely what were John's choices and needs and then how to support those needs. After that, things got a lot better for John and he was more understood and appreciated. His vocational manager found a job John loved, with more personal attention. The residential program strived to hire sympathetic staff with more training about John's individuality, and the whole team met monthly to talk about concerns and joys. I think Quality Assurance Reviews attached to licensing are the best possible method of client care!

Ani Lufkin

Personal story written to support Senate File 1934/ House File 1360.

Written by: Kelli Gillespie, direct support professional of 18 years.

The VOICE review meant a great deal to Gene. He has shared what took place at his review with his family, friends, and coworkers. He proudly displays pictures that were taken at the review all over his home and they have become conversation starters for all of those who visit.

VOICE has made a positive difference in Gene's life. Gene felt comfortable in telling the reviewers what his dream job was, and as a result of this review a few weeks later he got that dream job. His team had worked on finding him jobs in the past and always hit dead ends. But when the outside QA members came in it made a huge difference. As a result of that Gene is more positive, outgoing, and smiles most of the time now. He is like a new person. He is so happy now, and appears to be out of the slump he was in for the past year or two when he would bounce around from one job to the next. QA made the team realize that dreams can happen and we have to pursue them until they happen.

Funding for Quality Assurance VOICE reviews should continue. I used to work in another county that did not have the QA reviews. What a positive difference it has been working in a county that does QA reviews. I have been through 4 reviews with individuals in the past couple of years and after each one I have seen so many positive improvements and had better knowledge in providing a better service to individuals. I look forward to being part of the next review and learning even more about the individuals, team, and myself as a direct care staff person. I think the reviews make me a better employee in this line of work. I wish everyone could experience this as it is a very positive experience.

As far as QA licensing involving so many people and the importance of that I think the above statements speak for that. Instead of people being nervous because licensing is coming, I see people excited that QA is coming. People are pumped to show the great work they do and seem eager to take in any new information and use it to benefit the individuals they work with.

Sincerely,
Kelli Gillespie

I am a staff member in a group home who has worked in this field for 18 years. I have only been a part of the area where QA reviews have taken place for 4 1/2 years. I wish QA had been a part of my work since the beginning as it is so positive in every aspect!

April 7, 2005

Senator Linda Berglin
309 State Capitol Building
75 Rev. Dr. Martin Luther King Blvd.
St. Paul, MN 55155-1606

Re: SF 1934

Dear Senator Berglin:

I hope the legislative session is evolving in a satisfactory manner for you. As always it is a great comfort to me and so many others to know that you are there, alert to the needs of Minnesota's most vulnerable citizens and committed to their well-being.

I am writing today with regard to a specific program, The Region 10 Quality Assurance Commission, and piece of legislation (SF 1934). As a bit background, I have followed the evolution of the Commission and its program since its inception. Some have been overly generous in tracking its origins from a challenge I made to the Region 10 Developmental Disabilities "Stakeholders" group nearly a decade ago. I would be proud of having influenced the creation of this remarkable undertaking, but again I find such attribution very generous. What I do know for sure is that the Region 10 Commission has become a national model of high visibility and high influence to initiatives in many states to reconceptualize, reinvigorate and redesign what is meant by and achieved by quality assurance systems for community members with disabilities. In the past five years I can think of no other innovation in human services in Minnesota that has achieved the level of attention, esteem and influence nationally as has the Region 10 Commission. Every year the University of Minnesota and the National Association of State Directors of Developmental Disabilities Services co-sponsor a national conference entitled "Reinventing Quality". It highlights the most notable innovations in the US to create better systems of support for citizens with developmental disabilities. Each year for the past 5 years we have invited the Region 10 Commission to present its program. Each year in the conference evaluation we ask the conference attendees to rate: a) the quality and contribution of each session, and b) whether the session should be part of the program in the next year. Based on this feedback, two programs have been repeated every year, the Region 10 Commission being one of them. I say all of this to establish that nationally the Commission is viewed as an exciting and highly relevant effort to support and improve community life for people with developmental disabilities. It is seen as a remarkably positive effort to bring the light and energy of community to a quality assurance function that is viewed in Minnesota and other states as typically bureaucratic, disconnected from individual and community goals and values, and of little tangible benefit to quality as it is understood and desired by people with disabilities, their families and others who care about them. The Commission is community at its best and Minnesota at its best, and it brings much credit to Minnesota.

I know that you must ultimately ask, national accolades notwithstanding, what is the immediate interest of Senate File 1934 (and SF 1935) to Minnesota and to its citizens with disabilities. I think the answer to that lies in what it has been confirmed to mean in Region 10 and also the interest that has been generated in this model within other regions around the state. I know there is high interest in the Southwest part of the state in replicating the Region 10 model of quality assurance program that would be led by the Arc of Southwest Minnesota. I know that there is

Senator Beglin-2

substantial interest in Blue Earth and Martin Counties. I know that there the Metro chapters of The Arc are exploring pilot program with Hennepin county officials. I know that meetings have been held in St. Cloud in which stakeholders are exploring the possibilities of implementing the VOICE review process developed and used by the Region 10 Commission.

The outcomes being achieved in Southeast Minnesota through the Region 10 Commission are desired by others. They are desired because people believe that quality assurance should not be a bureaucratic process designed just to put the heat on the very worst performing organizations, but should be a program that elevates the quality of all organizations. People believe that people with disabilities and family members should be part of quality assurance teams because they have the most to gain and the most to lose when the "quality" in quality assurance becomes a separated from "quality" in the lives of individuals and families. People believe that quality assurance teams should involve people with a wide range of perspectives on quality (service recipients, family members, case managers, agency administrators and direct support staff) and not relegated to people who do nothing but quality assurance review and have little other relevant experience by which they can evaluate and contribute to the performance of others. People believe that quality assurance programs should hold people accountable for their commitments to people as well as their compliance with rules. People believe that quality assurance should increase service providers' knowledge of and communication with the people they support.

The Region 10 Quality Assurance Commission is a Minnesota original. It is of Minnesota and I know it has the opportunity to bring the best of Minnesota to a process about which most people are deeply cynical if they care enough to have any attitude at all. Most people have decided that quality assurance is essentially pro-forma and of minimal benefit to the vast majority of Minnesotans with developmental disabilities. I think we are as a state extremely fortunate to have a group of citizens who have stood up to say we shouldn't accept that. We shouldn't accept that for people with disabilities and we shouldn't accept that as a use of public resources.

I hope you will give your full consideration to the long-term benefits of assuring that there is an opportunity for communities to play a meaningful role in community quality assurance. Thank you very much.

With deepest and enduring respect,

K. Charlie Lakin

cc: Senator Larry Pogemiller

**Senate Counsel, Research,
and Fiscal Analysis**

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Senate

State of Minnesota

S.F. No. 1935 - Study on Licensing and Alternative Quality Assurance (The Delete-Everything Amendment)

Author: Senator Sheila Kiscaden

Prepared by: David Giel, Senate Research (296-7178) 

Date: April 11, 2005

S.F. No. 1935 requires the Department of Human Services (DHS) to arrange for a study of statewide development and implementation of regional or local quality assurance models for disability services.

The study must include a review of current projects or models; must make findings regarding the best components, role, and function of such models within a statewide quality assurance system; and must include cost estimates and funding sources for regional and local quality assurance models on a statewide basis.

The study must be performed in consultation with a variety of interested parties listed in the bill.

DHS must submit the study by July 1, 2006, and proposed legislation for implementation of a statewide quality assurance system by December 15, 2006, to chairs of the appropriate legislative committees.

DG:rd

1 of Human Services can administer a statewide quality assurance
2 licensing system and exploring the benefits and problems in
3 using such an independent entity;

4 (4) proposing an organizational structure, including
5 community-based regional implementation for a quality and
6 licensing system;

7 (5) developing recommendations on the amount and sources of
8 funding necessary for a statewide quality assurance and
9 licensing system, including consideration of whether federal
10 Medicaid administrative funds and a portion of home and
11 community-based services waiver funds can be used and, if so, to
12 what extent; and

13 (6) developing recommendations on implementation of a
14 statewide system of quality assurance and licensing for a final
15 report.

16 Subd. 4. [MEETINGS.] At a minimum, meetings of the task
17 force must be conducted according to Minnesota Statutes, chapter
18 13D. During the 2006-2007 biennium, the task force must meet at
19 least quarterly.

20 Subd. 5. [REPORT.] The task force shall report to the
21 legislative committees with jurisdiction over health and human
22 services with recommendations on implementation of a statewide
23 system of quality assurance and licensing by December 15, 2006.

1 Senator moves to amend S.F. No. 1935 as follows:

2 Delete everything after the enacting clause and insert:

3 "Section 1. [DIRECTION TO THE COMMISSIONER; LICENSING AND
4 ALTERNATIVE QUALITY ASSURANCE STUDY.]

5 The commissioner of human services shall arrange for a
6 study, including recommendations for statewide development and
7 implementation of regional or local quality assurance models for
8 disability services. The study shall include a review of
9 current projects or models; make findings regarding the best
10 components, role, and function of such models within a statewide
11 quality assurance system; and shall estimate the cost and
12 sources of funding for regional and local quality assurance
13 models on a statewide basis. The study shall be done in
14 consultation with counties, consumers of service, providers, and
15 representatives of current projects, including the Region 10
16 Quality Assurance Commission.

17 The study shall be submitted to the chairs of the
18 legislative committees with jurisdiction over health and human
19 services with recommendations on implementation of a statewide
20 system of quality assurance and licensing by July 1, 2006. The
21 commissioner shall submit proposed legislation for
22 implementation of a statewide system of quality assurance to the
23 chairs of the legislative committees with jurisdiction over
24 health and human services by December 15, 2006."

25 Amend the title accordingly