

A letter in support of Lilly Cheney

Dear Senator Monnes Anderson and members of the Senate Committee on Health Care,

I am writing in support of SB 215 which will help ensure our daughter Lilly will receive proper medical treatment.

You see, our daughter Lilly has a rare disease. She has Addison's disease (also called Primary Adrenal Insufficiency) Each time we take our daughter to the ER, we have to educate all the medical staff that comes in to contact with her about her condition and how to treat it because people with her disease are only 10 in a million. Without proper treatment, a simple stomach flu or broken leg can be fatal. If she does receive the proper treatment, she has a very good chance of recovering.

Unfortunately her disease is one of 7,000 rare chronic conditions. How is a doctor supposed to track all 7,000 diseases and treatments? It is impossible.

SB 215 sets up a rare disease database called ORDER (Orders for Rare Disease Emergency Response). This database will provide the tools healthcare providers need to save lives like our precious girl Lilly.

Since ORDERS will come from the physician who treats Lilly's condition, providers will have the assurance and information they need to provide prompt and proper treatment.

Sincerely,
Ken and Debbie Cheney



I know and support the Cheney Family. PLEASE VOTE YES ON SB 215

Peggy Salyers
Printed name
Peggy Salyers
Signature

Laurie Miller
Printed name
Laurie Miller
Signature

Shelley Fitch
Printed name
Shelley Fitch
Signature

JUNE YUN
Printed name
[Signature]
Signature

Marilyn Bengtson
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Signature

Sarah Fawcett
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Jennifer Patton
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Sharon Rogala
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Sandra Copp
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Julie Hayes
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Linda Butterfield
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Deanna Faris
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DeAnn Womack
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SB 215 sets up a rare disease database called ORDER (Orders for Rare Disease Emergency Response). This database will provide the tools healthcare providers need to save lives like our precious girl Lilly.

Since ORDERs will come from the physician who treats Lilly's condition, providers will have the assurance and information they need to provide prompt and proper treatment.

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Nancy L. Steiber
Printed name

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Signature

Linda L. Blakey
Printed name

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Signature

Robyn Campbell
Printed name

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Dianne Striefel
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Sheri Antoniskis
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Suzanne Leica
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JANET MACON
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Our daughter Lilly has a rare illness-Addison's disease (also called Primary Adrenal Insufficiency) Each time we take our daughter to the ER, we have to educate all the medical staff that comes in to contact with her about her condition and how to treat it because people with her disease are only 10 in a million. Without proper treatment, a simple stomach flu or a broken leg can be fatal. If she does receive the proper treatment, she has a very good chance of recovering.

Unfortunately her disease is one of 7,000 rare chronic conditions. It is impossible for a doctor to track all those diseases and how to treat them.

SB 215 sets up a rare disease database called ORDER (Orders for Rare Disease Emergency Response). This database will provide the tools healthcare providers need to save lives like our precious girl Lilly in an emergency!

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WILLIAM ALBRECHT
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William Albrecht
Signature

Carol Albrecht
Printed name

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Signature

SUSAN WILSON
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Susan Wilson
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Kristina Martinez
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Kristina Martinez
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Mary Forrestall
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Mary Forrestall
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Virginia Hubbs
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Stephan Derhau
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Catherine Newberry
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Grace C. Saylor
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John McHone
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