



Let's get Down to it...

April 2015

www.lldss.org

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Upcoming Events

- April 9th - LLDSS Meeting, 6-8, Erin's Pavilion
- May 14th - LLDSS Meeting, 6-8, Erin's Pavilion
- June 5 - LLDSS Golf Outing
- July 14 - LLDSS Meeting, 6-8, Erin's Pavillion

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A Message from the President

Greetings LLDSS Members!

I would like to begin this quarter's newsletter by expressing my gratitude and thanks to our wonderful Board of Directors. For the first time that I can recall, we were asked as a group to support legislation that affects persons with Down syndrome and their families. I presented the Board with what had been brought to my attention and each worked seamlessly to represent our group as a whole. They took unto them a responsibility to make sure our group was both represented and respected. Some took time off of work to attend committee meetings at the Capitol, others followed closely online. The point is, it isn't often we get asked to represent our group in a bill that will benefit future members and their families in perpetuity. Much of what we focus on is the immediate future, however on March 13th, 2015, LLDSS voted to support HB3158 which is new legislation that has been proposed in Illinois requiring the Illinois Department of Public Health to make available up-to-date and accurate information about Down syndrome. This information may be provided by health care providers and genetic counselors to expectant or new parents who receive a diagnosis of Down syndrome and is comprised of the following:

- Up-to-date and evidence based written information about Down syndrome reviewed by medical experts and the national Down syndrome organizations.
- Current contact information for local support groups.

Why is this legislation needed?

- For many new or expectant parents, receiving the news of a diagnosis of Down syndrome is one the most critical moments of their lives. At the time of the diagnosis, and in the immediate aftermath, access to current information and local support are essential for both families touched by Down syndrome and the medical professionals who serve them.
- Today, when patients receive a prenatal or postnatal diagnosis of Down syndrome, the information they receive may be accurate and up-to-date, but more commonly it is outdated, not reviewed by medical experts, and not endorsed by national Down syndrome organizations. At worst, it can be archaic and offensive.
- Unfortunately, health care providers across the state are consistently distributing inaccurate and outdated information to patients who receive a Down syndrome diagnosis.
- The lack of consistency and accuracy in the information distributed often conveys an outdated portrayal of the lives of people with Down syndrome in society today.
- The need for current information is growing. As a result of advances in medical technology, it is now recommended that all pregnant women be offered the option of non-invasive prenatal screening tests for Down syndrome.

Background

- The Illinois Down Syndrome Information and Awareness Act is modeled after legislation supported by the National Down Syndrome Society (NDSS), as well as the federal Prenatally and Postnatally Diagnosed Conditions Awareness Act (S.

Useful Links

Lincoln Land Down Syndrome Society
<http://www.LLDSS.org>

National Down Syndrome Society
<http://www.ndss.org/>

Sparc <http://www.spfldsparc.org/>

United Cerebral Palsy Land of Lincoln
<http://ucpll.org/>

PUNS List Information
<http://www.dhs.state.il.us/page.aspx?item=47620>

LLDSS Facebook
<https://www.facebook.com/pages/Lincoln-Land-Down-Syndrome-Society/100514010032422>

Down Syndrome Association of Greater St. Louis
<http://dsagsl.org/programs/community-groups/>

LLDSS Moms Group
<https://www.facebook.com/groups/404921159550855/?fref=nf>

Contact Us

Website
www.LLDSS.org
Facebook –[click here](#)
Twitter @TheLLDSS

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1810), co-sponsored by Senators Edward Kennedy (D-MA) and Sam Brownback (R-KS) enacted in 2008.

- Down syndrome “information legislation” has currently been passed in 10 states.

At the core, this bill expresses much of what our group establishes as our vision. If this bill passes and becomes law, your LLDSS Board will have played a pivotal role in its success. For that I want to thank our board on behalf of our wonderful group.

Very Kindly,

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News and Noteworthy



The Lincoln Land Down Syndrome Society is having their 10th Annual Golf outing this year on June 5th at Edgewood Golf Course in Auburn. Jason Schnepf and Ryan Johnson are already hard at work securing donations and preparing the registration letters to hit your mailbox. Registration is set to go LIVE on April 1st so if you know a golfer, point them to our website to register. www.ildss.org Spots fill quickly so don't hesitate!

LLDSS was contacted recently by the illustrator of a children's book specifically about children with Down Syndrome. The book, *Hansel and Gretel, A Fairy Tale with a Down Syndrome Twist* is on shelves now. Disability advocate and author Jewel Kats writes about, Hansel, a courageous hero with Down syndrome. The illustrator, Claudia Lenart was kind enough to ship our group a free copy to display at our moms group on April 9th.

Deb Gossrow, aka Moms Group guru extraordinaire, is planning a summer road trip to the Chicagoland area. Early plans are to rent a van of some sort and head to GiGi's playhouse and Lambs Farm. For those of you who aren't familiar with either, I highly encourage you to look into this. <http://gigisplayhouse.org/> and <http://www.lambsfarm.org/> are the websites. Both are wonderful places. GiGi's playhouse has sites statewide and facilitates job development for people with disabilities, but primarily Down Syndrome. Serving children and adults of all ages, they offer 30 educational and therapeutic programs at no charge to families. All programs aim to maximize self-confidence and empower individuals to achieve their greatest potential. Their literacy program alone teaches thousands of kids with Down syndrome to read every year! The 2nd stop is Lambs Farm; to their residents, Lambs Farm is home, and a place they are proud to share with their visitors. To their visitors, Lambs Farm is also a place to grow through enriching experiences with people with developmental disabilities. If you are interested in joining this trip, reach out to Deb Gossrow on the Facebook Moms Group, or contact me and I will put you in touch with her.