



# Down Syndrome Association of Greater St. Louis

benefiting the lives of people with Down syndrome and their families through individual and family support, education, public awareness and advocacy

## Advocacy E-News

Happy New Year! The Down Syndrome Association of Greater St. Louis is excited to announce that we will be increasing our advocacy efforts in 2018 and beyond. We look forward to partnering with other great agencies in the community to ensure that our loved ones with Down syndrome and other disabilities have a voice both in Jefferson City and in Washington, D.C. Now that the 2018 Missouri legislative session is underway, we are asking you, our members, for feedback, and to join our Advocacy Committee. We will also be periodically sharing with you information you need to know about legislative issues in our state and country.

### Join our Advocacy Committee!

The DSAGSL Advocacy Committee welcomes parents, siblings, and interested community members for our monthly calls. Our next call will take place on January 30<sup>th</sup> at noon and will be held every month on the fourth Tuesday. No advocacy experience required! Contact [Erin@dsagsl.org](mailto:Erin@dsagsl.org) to join the monthly call.

### What are Your Priorities?

We want to hear from you! Let us know what is important to you when it comes to legislative issues and the Down syndrome community. [Click here](#) to take our quick poll!

## Save The Date!

Mark your calendars for the 2018 Disability Rights Legislative Day on Wednesday, March 13, 2018, at the Missouri Capitol. On this day, hundreds of disability rights advocates from across the state come together to make their voices heard. We hope you can join us! RSVP to [Erin@dsagsl.org](mailto:Erin@dsagsl.org)



Look out for more information on our upcoming March 6th advocacy training!

E-mail [Andi@dsagsl.org](mailto:Andi@dsagsl.org) with questions and for more information.

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## Share your Medicaid Story and Help Prevent Cuts!

Our partners at Paraquad, People First and St. Louis University are looking for stories about how Medicaid funded programs have affected the real lives of people with disabilities. The stories would be used to increase our communities' capacity to advocate effectively and would help prevent cuts which would put people at risk of losing vital services that contribute to their independence. They may be shared with media outlets, legislators, or serve as a guide for the community member to tell their story in another public setting. This is a real source of power for our community, the ability to share our lived experiences, and this project is a way for us to build that power.

If you are interested in sharing how Medicaid funded programs benefit your family member's life, please complete the form at <https://goo.gl/forms/O7p80uKxKSSboQQt2>. Paraquad and SLU Law students would come to your home or call you over the phone to collect your story, and help you shape your own story into a sharpened tool for advocacy!

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## Call Your Senators to Support Kevin and Avonte's Law

The National Down Syndrome Society (NDSS) is working hard to pass Kevin and Avonte's Law at the Federal level. This law is named in honor of two boys with autism who perished after wandering. Nine-year-old Kevin Curtis Wills wandered from home, slipped into Iowa's Raccoon River and drowned in 2008. Fourteen-year-old Avonte Oquendo wandered away from his school and drowned in New York City's East River in 2014.

Kevin & Avonte's Law would amend the Violent Crime Control and Law Enforcement Act of 1994, reauthorize the expired Missing Alzheimer's Disease Patient Alert Program and include new provisions to support people with autism and other intellectual/developmental disabilities who wander. NDSS supports this legislation, as wandering is a significant problem in the Down syndrome community. The bill would enhance the safety of individuals with Down

syndrome who wander and provide peace of mind to their families.

The bill has passed in the Senate via voice vote. We need advocates to reach out to Members of the House and request that they co-sponsor the bill.

Click the link below to log in and send your message:

<https://www.votervoice.net/BroadcastLinks/LXzYgLVUp5WtzAOBlAJt7Q>

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## Missouri Bills to Watch

*(Summarized by our friends at [Paraquad](#))*

- Senate Bill 699 sponsored by Sen. Scott Sifton, D-Affton, and House Bill 1527 sponsored by Rep. Cora Faith Walker, D-Ferguson, would make changes to the current Ticket to Work Health Assurance Program and provide more opportunities for people with disabilities to work and still retain necessary services like personal attendant care.
- Senate Bill 562 sponsored by Sen. David Sater, R-Cassville, would require the state of Missouri to apply for a global waiver that would reduce funding for MO HealthNet, Missouri's Medicaid program, possibly resulting in waiting lists, eligibility restrictions or service restrictions for the program.
- Senate Bill 567, sponsored by Sen. Mike Cunningham, R-Rogersville, would modify the Missouri Property Tax Credit, also known as "circuit breaker," for people who are 65 or older and people with disabilities by reducing the maximum allowed credit from \$1,100 to \$750 for homeowners and from \$750 to \$450 for renters. This bill would also reduce the maximum income threshold for eligibility to 100 percent of federal poverty level. In addition, the savings acquired from this change would be deposited in the Missouri Senior Services Protection Fund, which would then be used to increase the Medicaid fee-for-service reimbursement rate to nursing homes.
- House Bill 1241 sponsored by Rep. Deb Lavender, D-Kirkwood, would modify the Missouri Property Tax Credit by reducing the maximum tax credit allowed for renters from \$750 to \$650 and for homeowners from \$1,100 to \$1,000. It would also use the money saved, along with sweeps from other funds, to restore \$22 million to the Missouri Senior Services Protection Fund and \$6 million to MORx, Missouri's state pharmacy assistance program.

