



# “Together we make a difference!”

## 2022 Advocacy Update – Off to a big start!

The year is off to a big start for the New York State bleeding disorders community! [3 key bills we support and you advocated for were signed into law by Gov. Kathy Hochul on New Year’s Eve](#) and will help protect access to the medications we need in 2022.

**S3566/A5854A Pharmacy Access Reform** – this law closes a loophole in a 2011 law preventing health insurance companies and PBMs from forcing patients to use a mail order pharmacy. Under the new law patients should have equal access to a mail order or local in-state pharmacy for their medications. This law took 10 years of hard work by the community and many others to pass and proves the power of persistence!

**S3762/A1396 PBM Regulation** – PBMs, or Pharmacy Benefit Managers, are companies that manage many of our medication benefits and often limit patient access to expensive medications. In most states these companies are not regulated. Thanks to a recent Supreme Court ruling (*Rutledge v PCMA*) and this new law, New York State will lead the country in requiring PBMs to follow specific rules for how they operate to make sure profits aren’t put ahead of you and the care you need.



*Governor Kathy Hochul at the recent State of the State speech.*

**S4111/A4668 Mid-year Formulary Changes** – also known as Non-Medical Switching. This bill was vetoed by former Gov. Cuomo, but patient groups like NYSBDC persisted and won over Gov. Hochul. Under this law health insurance companies and PBMs can’t move your

medication to a higher payment tier or change the rules for how you get it during your plan year (usually January to December). Unfortunately, Medicaid patients were not covered by this law, though they do have other protections in place.

**Assemblyman Richard Gottfried to retire** – If you’ve been to Albany Days or follow the news you’ve heard of Assmb. Gottfried. He is the longest serving member of the NYS Legislature in history (52 years) and a huge force behind better, more affordable care for New Yorkers. In 1991 Assmb. Gottfried led the creation of the first in the nation Child Health Plus (CHP) program which has provided care to many children with bleeding disorders.



He’s been active on every major health care issue in his 52 years, including efforts to reform prior approval rules this year.

*Assmb. Richard Gottfried at a health care rally.*

Assmb. Gottfried has been a tireless champion of better care for everyone and a long-time friend of the bleeding disorders community (his picture is on our website). We wish him and his wife many long and happy years together in retirement!

**Remember to advocate!** As Randi Clites, a mom and longtime advocate says, “We are small, but we are mighty!” When you e-mail legislators, post on social media, come to Albany Days, or talk to someone about bleeding disorders, you make an impact. And when we come together to do these things, we can make a big difference for our community!