

## Causes

When then 14-year-old daughter Lauren was diagnosed with hydrocephalus, her mother Rebekah Wright quickly began looking for ways to help her family educate themselves about the journey to come. Simply put, hydrocephalus is a condition where there is too much fluid in the cavities of the brain. If left untreated, it can cause nausea, headaches, inability to stand or balance, memory loss, vision issues and epilepsy. "I work in healthcare so I knew what hydrocephalus was and the severity of the disease," notes Wright.

However, when she began looking for support for herself and her family, Wright found that there was no Louisiana state group dedicated to hydrocephalus. Instead of giving up or becoming frustrated, Wright went straight to the top: she contacted the founders of the national organization -The Pediatric Hydrocephalus Foundation- and began the process of starting a Louisiana chapter.

The local group offers support to parents and families dealing with hydrocephalus. Additionally, Wright takes time off from her job to attend doctor visits, check-ups or surgeries with families in need. Yet, Wright can't take care of everything herself. "Our biggest issue is not enough people know about us yet," Wright says.

Because the organization is 100 percent non-profit, the Louisiana sector is in serious need of people willing to donate their time and energy. "All of our volunteers either have the condition or are parents of a child that does," Wright says. Further, no salaries are paid or overhead costs derived from a budget because every cent raised by the group goes directly toward finding a cure.

Wright has worked within the community to raise awareness for hydrocephalus and has gathered some support from Senators R.L. "Brett" Allain and Sam Jones, who are working with her to pass two bills on behalf of those afflicted with the disease. They are also working to create a national day of awareness and a license plate to bring support and attention to the cause. Wright says the Ice Gators Hockey Team works with her and the Louisiana chapter as a big sponsor, offering group game nights and much needed support to the families.

In August 2014, Wright and her daughter will travel to Washington D.C. to lobby Congress for awareness of the disease. Those interested in donating time or funds to the PHF Louisiana Chapter should contact Wright via email at [rwright@hydrocephaluskids.org](mailto:rwright@hydrocephaluskids.org) or visit their Facebook page. All donations are tax deductible and go towards helping the Louisiana chapter.

— By Samantha Stevens



# Rebekah WRIGHT

*"You shouldn't have to go through this alone and Lauren and I are committed to helping the next family through their journey with hydrocephalus."*

—Rebekah Wright