

ADHD Medication Shortages: You Helped CHADD Make a Difference

By Ruth Hughes, PhD

IT HAS BEEN A VERY LONG YEAR of dealing with medication shortages across the country. The information you shared with us last winter was often heartbreaking, as you described the incredible steps you were forced to take to obtain medication for yourselves or your children, the skyrocketing prices charged by some pharmacies, and the awful consequences of not having medication.

CHADD worked hard to address the situation, and we are seeing some real changes take place, both in resolving the immediate shortages and in solving the problem long-term. We worked closely with legislators, peer associations, government agencies, and pharmaceutical companies to get to the causes and to address them.

The Drug Enforcement Agency appears to have played a key role in the shortage. The DEA's mission is to ensure that stimulant medications are not abused or misused. Every year DEA sets a quota for each pharmaceutical company, and the company may not manufacture even a single pill above this limit. If the quota does not accurately reflect the legitimate need, or if medications are diverted for nonmedical use, then a shortage can occur. Until now there has been no mechanism for a shortage to be addressed once it occurs. That is about to change.

We addressed this very serious problem through the following actions:

- CHADD's online survey in January collected more than 5,500 responses. Forty-nine percent of the respondents were having difficulty getting prescriptions filled, and eighteen percent were forced to change to a new medication. Your participation in the survey gave us more information on the shortage than anyone else in the country.
- CHADD and the American Academy of Child and Adolescent Psychiatry formed a coalition of concerned associations, which included several pharmacist groups as well as the American Academy of Pediatrics, the

American Psychiatric Association, and a number of mental health and ADHD groups.

- CHADD has been in regular communication with all the major pharmaceutical companies to understand the obstacles to manufacturing sufficient quantities of medication.
- CHADD leadership has met with staff from every key committee in both the US House of Representatives and the Senate to make them aware of the seriousness of the problem.
- CHADD leadership and members of the coalition met with the staff of the Food and Drug Administration to determine the FDA's role.
- CHADD worked with the media to get the story out to the larger community. Literally hundreds of media outlets covered the story.
- And the coalition repeatedly asked for a meeting with the Drug Enforcement Agency. We are still waiting.

Have we made a difference? You bet we have.

- In January, the DEA increased the quota for stimulant medications significantly. Because the pharmaceutical companies need time to then manufacture the medications, an increase in the availability of medications did not begin until this spring.
- The House Energy and Commerce Health Subcommittee is investigating the role of the DEA in the shortage and has not yet released a report.
- Senator Chuck Grassley from Iowa has asked the General Accounting Office to investigate the DEA's role and report on their findings. While such a report can take up to a year, the GAO is known for even-handed, nonpartisan reports and good recommendations.
- The **Prescription Drug User Fee Act of 2012** was approved by the House in June 2012 and faces one last vote in the Senate before going to the President. It instructs the Secretary of Health and Human Services to address medication shortages

within thirty days. When the shortage involves a controlled medication like stimulants, the Secretary has the authority to contact the Attorney General (the Secretary's counterpart in the Department of Justice, which includes the DEA) and ask that the quota be increased. The Attorney General and the DEA must respond by either taking action or responding with a clear rationale for not increasing the quota. And all of this information must be made public. This is the first time a mechanism has been put in place to address a shortage before it becomes chronic.

In late June, we wanted to ascertain whether the crisis had truly passed. So we set up another online survey to gauge whether people have access to their medications. I'm pleased to report that only 688 people reported they were still having difficulty getting prescriptions filled.

Thank you for participating in our surveys and for helping CHADD to make a difference! 🙌



Ruth Hughes, PhD, is the CEO of CHADD. An earlier version of this story appeared on the CHADD Leadership Blog on June 25, 2012.