

## **ANESTHESIA SURVEY**

Anesthesia and Williams syndrome: A Hot-Button Topic. Do you have concerns about your family member with Williams Syndrome receiving anesthesia? Persons with Williams syndrome, especially children, are more likely to experience adverse reactions, including sudden death, with anesthesia or sedation during surgery and procedures. Researchers are trying to identify possible risk factors for this and other complications.

You can help researchers solve this problem by providing information to the Registry's "Anesthesia and Procedure" Survey and, then, allowing the Registry staff to work with you to collect the actual medical records for each surgery and procedure.

From those of you who already completed the Survey, the Registry has learned:

- a) On average, each person with WS had 3.5 surgeries or procedures.
- b) However, there is a range. Some persons had "no" or only one surgery, while others had multiple surgeries or procedures (9, 10, or more).
- c) The most serious complication, cardiac arrest, was reported in 1%.
- d) You reported a higher overall complication rate, ~20-25%. However, many of these complications were not life-threatening. Some of them were likely due to the surgery itself and not necessarily the anesthesia.

To further knowledge and understanding about anesthesia risks, it is important to get exact information about surgeries and procedures (including what anesthesia and medications were used) from as large a number of persons with WS as possible. The Registry is set up to do this! The place to start is with the "Anesthesia and Procedure" Survey. If you want to learn more about the Survey, complete it, or update it, by logging in to your Registry account!

Consider joining the Registry! If you're already a member, log in to the Registry to share or update information about your family member with WS: [www.williams-syndrome.org/registry-families](http://www.williams-syndrome.org/registry-families).

Numbers like these become very powerful when more families answer the Registry's Health Survey. Please help the Registry grow to better serve you and support research efforts!