

Prader-Willi Syndrome Association (USA)

AUTOPSIES TO HELP UNDERSTAND GI RELATED DEATHS

Ann Scheimann, M.D. is a pediatric gastroenterologist at Johns Hopkins Hospital and the most nationally renowned physician on GI issues with Prader-Willi syndrome (PWS). She recommends that when doing an autopsy you should include a careful histological examination of the stomach, colon, liver, pancreas and any other organs that you think would be appropriate so that we can acquire a better understanding of our GI related deaths in individuals with PWS. Even if the death is not GI related, it will help us understand the physiology of the PWS GI system. Look at distention, check vessels and stages of margins if there was surgery, and the general quality of the stomach lining. We have a committee that is studying PWS deaths.

In addition, we may ask that slides or paraffin embedded blocks be sent to Dr. Fiona Graeme-Cook at Mass General for correlation with the other Prader-Willi syndrome cases. She was the pathologist on the article on *Acute Idiopathic Gastric Dilation With Gastric Necrosis In Individuals With PWS*. Her contact #'s are: 617-726-2000 to page, or her office at 617-724-1578.

Dr. Scheimann has PWS clinics in two states, but is primarily in Baltimore. Her contact information is:

- (410) 283-4900 nationwide pager for medical staff only
- (410) 955-8765 (Baltimore)
- 832-822-3131 (Houston)

**Prader-Willi Syndrome Association (USA)
Sarasota FL 34242, USA**

**Telephone: 941-312-0400
1-800-926-4797 (toll-free in USA and Canada)
FAX: 941-312-0142**

**Web site: www.pwsausa.org
E-mail: national@pwsausa.org**

**Janalee Heinemann, MSW
Director of Research & Medical Affairs
Cell # 941-685-6044**