Defining Moments in *MMWR* History: Toxic Shock Syndrome -- 1980

[Announcer] This program is presented by the Centers for Disease Control and Prevention.

[Dr. Rasmussen] Welcome to *Defining Moments in MMWR History*. I'm your host, Dr. Sonja Rasmussen, Editor-in-Chief of the *MMWR*.

In the late 1970s and early 1980s, an outbreak of a disease called Toxic Shock Syndrome made healthy women sick. CDC's disease detectives helped unravel the link between Toxic Shock Syndrome and high-absorbency tampons.

Today, I'm talking with Dr. Kathy Shands, former chief of the Toxic Shock Syndrome Task Force and one of CDC's original disease detectives who worked on this outbreak. Dr. Shands received a U.S. public health service commendation medal for her work on Toxic Shock Syndrome. Thank you for coming, Kathy.

[Dr. Shands] Thank you for having me.

[Dr. Rasmussen] For those who aren't familiar with Toxic Shock Syndrome, what is it and what are the signs and symptoms?

[Dr. Shands] Toxic Shock Syndrome is a severe multi system disease that, especially at the time we were working on it, occurred primarily in young women. It's characterized by high fever; hypotension, or low blood pressure, that's where the 'shock' part of the name comes from; a sunburn-like rash; and later, peeling of the skin, especially the palms and soles. Many organ systems can be involved, including GI, muscle, kidney, liver, blood, central nervous system, and mucous membranes. It's caused by a toxin that's produced by *Staphylococcus aureus* organisms. That's where the 'toxic' part of the name comes from. It can be very serious. Many patients end up in intensive care units, and the case facility rate is five to 10 percent.

[Dr. Rasmussen] How are patients with Toxic Shock Syndrome treated and is the treatment usually effective?

[Dr. Shands] They are treated primarily by supportive measures, such as large volumes of intravenous fluids. Antibiotics that are effective against *Staph aureus* are also used, but it's not clear that they're helpful in cases associated with tampon use. Treatment is usually effective, but if TSS is not caught early, or if the illness is particularly severe, patients can die in spite of treatment.

[Dr. Rasmussen] What did experts at CDC do when they first heard about these cases?

[Dr. Shands] We first heard about them in January 1980 when the state epidemiologist in Minnesota called CDC to report nine cases occurring in Minnesota and Wisconsin. Our first response was to create a case definition, and then we began passive surveillance of the disease, meaning we accepted calls and letters from physicians and public health workers and determined whether or not they met the case definition.

[Dr. Rasmussen] How did you and others at CDC first identify the cause?

[Dr. Shands] We had a lot of help from doctors around the country. Dr. Christian Schrock in Minnesota first recognized the association with menstruation, and Dr. Jeff Davis, the state epidemiologist in Wisconsin, first recognized an association with tampons. We conducted two case control studies. They both consisted of telephone interviews with women who had had the illness, or cases, and with friends of theirs who had not had TSS, the controls. We asked routine questions about age, marital status, and the timing of the illness, and more sensitive questions about menstruation, sanitary products used, and sexual activity. Our first study confirmed the associations others had seen with menstruation and with tampon use. And our second study found an association with a particular brand of tampons, Rely, that was made by Proctor and Gamble and was highly absorbent.

[Dr. Rasmussen] Once you made that association—that connection between the outbreak and the use of high absorbency tampons—how did you stop the outbreak?

[Dr. Shands] We worked with P&G and with the FDA to have Rely removed from the market. That removal decreased the incidence of TSS, but it did not make it go away. When Rely was introduced, other tampon manufacturers, in order to compete with this very popular, very absorbent tampon, had increased the absorbency of *their* products. After our second study was published and Rely was taken off the market, the other tampon manufacturers began to decrease the absorbency in their tampons and cases continued to decrease.

[Dr. Rasmussen] So did you get to the point where the cases completely stopped?

[Dr. Shands] No. After the removal of Rely from the market, as we interviewed more women who reported Toxic Shock Syndrome, we found that some had continued to use Rely and that some, a few, had actually gone out and bought up all the existing supplies of Rely tampons.

[Dr. Rasmussen] My goodness. So how did CDC communicate critical findings associated with this disease outbreak? How did you let the public and healthcare providers know about this?

[Dr. Shands] We used the *MMWR* on three very important occasions in 1980. May 23 to announce that, by that time, 55 cases of Toxic Shock Syndrome had been reported to CDC and to alert healthcare workers of the signs and symptoms of the disease and its severity; June 27 to announce the results of the first CDC study and similar studies in Wisconsin and Utah and to encourage continued reporting of the disease; and September 19 to announce the results of the second CDC study showing an increased risk of the disease associated with the use of Rely tampons. Each of these *MMWR*s, especially the one in September, generated lots of media interest. And all of us on the task force participated in many newspaper and magazine interviews, and I appeared on multiple TV news programs. In addition, the Utah state health department reported on its experience with TSS on October 17, 1980, in the *MMWR*, and we published a follow-up article in January 1981, reporting a decrease in the number of reported cases after September 1980. Since the time of the outbreak, three more articles updating information about the disease have been reported in the *MMWR*, in 1982, 1983, and 1990. An important note in these later publications is that Toxic Shock Syndrome does not only occur in menstruating women. It also occurs in women who are not menstruating and in men, in association with *Staph aureus* infections.

[Dr. Rasmussen] What were some of the lessons learned from the outbreak and the response?

[Dr. Shands] The two most important outcomes of this outbreak were first, the decrease in the number of cases, and secondly, new legal standards in maintaining confidentiality in public health research.

Because of the sensitive nature of the questions we asked, we felt it was critical to protect the names and answers given by participants in the studies. P&G was defending itself in numerous lawsuits, and we received repeated Freedom of Information Act requests from them and others for that information. Our legal team successfully blocked those requests and helped establish new laws to protect the confidentiality of future participants in public health research studies.

[Dr. Rasmussen] Thank you, Kathy, for joining me today. CDC's investigations into the historic Toxic Shock Syndrome outbreak substantially decreased Toxic Shock Syndrome cases and had a lasting impact on public health confidentiality. *MMWR* is proud of its role in communicating critical findings of this investigation and response.

For more information on this outbreak, or to learn more about the latest in public health, visit cdc.gov/MMWR.

Until next time, this is Dr. Sonja Rasmussen for *Defining Moments in MMWR History*.

[Announcer] For the most accurate health information, visit cdc.gov or call 1-800-CDC-INFO.