

## Case Report

# Support Groups for Patients Who Have Recovered From Thrombotic Thrombocytopenic Purpura

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Six years ago, we reported our initial experience with a support group for patients who had recovered from thrombotic thrombocytopenic purpura (TTP).<sup>1</sup> The goal of this report is to describe the continuing success of this program, both the 12 years of the Oklahoma TTP Support Group and the first year of the Kansas City TTP Support Group.

The Oklahoma TTP Support Group is a program of the Oklahoma TTP Registry; the Registry is a joint effort of the Oklahoma Blood Institute (OBI) and the University of Oklahoma Health Sciences Center. The OBI is the sole provider of plasma exchange services for 58 of Oklahoma's 77 counties; therefore, the Registry is an inception cohort of all patients in this region who were diagnosed with TTP or hemolytic-uremic syndrome and for whom plasma exchange was requested. Since it began in 1989, 393 consecutive patients have been enrolled in the Registry.

The Oklahoma TTP Support Group has three meetings each year; for each meeting a letter is sent to each patient in the Registry; meetings are in a University conference room and dinner is provided. Programs are focused on patient issues, with discussions led by a physician from the community. Programs often begin with a student presentation of data from the Registry; this format that is appreciated by patients and their families because they see students becoming familiar with their rare disorder, and they see how their own experiences are contributing to new knowledge about TTP.

The success of the Oklahoma TTP Support Group can be documented by two measures. First is the sus-

tained attendance. Across 36 meetings since 1996, the average attendance has been 20 patients and 19 additional family members and friends (Fig. 1). Patients include not only recent patients and their families who are anxious to learn more about TTP but also those who have regularly attended, year after year. During this 12 year period, meeting attendance would have been possible for 253 patients who survived their acute episode; 98 (39%) of these patients have attended at least one meeting. Remarkably, 22 patients have attended 10 or more meetings. All patients in the Registry who could have attending one of the Support Group meetings were analyzed to determine characteristics associated with attendance. Patients who have attended at least one meeting, when compared with patients who have not attended, were more likely to be women (84% vs. 67%,  $P = 0.004$ ), were more likely to have severe ADAMTS13 deficiency (activity <10%) and therefore be at greater risk for relapse (36% vs. 18%,  $P = 0.005$ ), and were somewhat more likely to have experienced a relapse (53% vs. 36%,  $P = 0.056$ ).

The second measure of success is the creation of a similar TTP Support Group by the Community Blood

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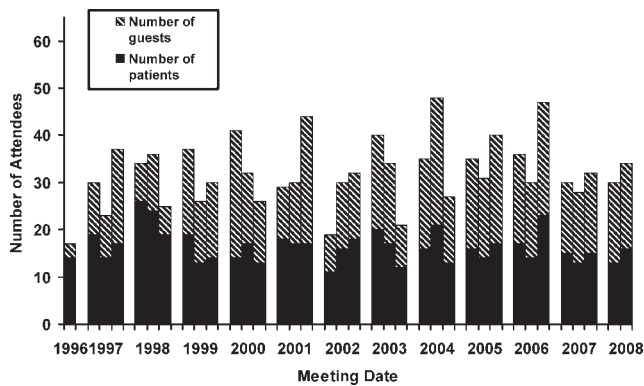


Fig. 1. Attendance at each of the 36 meetings of The Oklahoma TTP Support Group Study Group, 1996 to 2008. Meetings are held three times each year. Attendance of patients is indicated by the solid bars; attendance of family and friends is indicated by the hatched bars.

Center of Kansas City (KC). With advice and support from Oklahoma, the KC TTP Support Group held its first meeting in October 2007 and has had three meetings during its first year, attended by an average of five patients and 12 additional family members. Similar to the Oklahoma experience, families have repeatedly voiced their appreciation for the opportunity to talk with other patients and family members and to learn that they are not alone. The meetings have also been attended by community physicians and nurses, providing an opportunity to increase awareness of the issues faced by patients who have recovered from TTP.

The value of support groups for patients who have recovered from TTP can be documented by five measures. (1) The sustained attendance confirms the interest by patients and their family and friends in learning more about these rare syndromes. Different from groups that provide support to cope with a continuing or progressive disease, the value for our patients is information provided by both health professionals and other patients. To have suffered through a critical illness that is initially unfamiliar to the patient, her family, and even to her primary care physician is an alarming experience. Knowledge about TTP brings confidence and comfort. (2) TTP Support Groups provide a service to community physicians as well as to their patients.<sup>2</sup> Because many primary care physicians are not familiar with TTP, Support Group meetings fill a

need for information and provide an opportunity to answer questions. (3) The meetings are an important tool for maintaining patient follow-up. Documentation of long-term outcomes of patients with TTP has been the major research goal of The Oklahoma TTP Registry, and the regular announcements sent to all patients have become an integral component of our follow-up process. (4) An unanticipated value is that these meeting serve as focus groups, providing insights for new research questions. A major current research initiative of The Oklahoma TTP Registry is documentation of long-term outcomes following apparent complete recovery, using health-related quality-of-life measures and cognitive testing. Preliminary results of these studies have confirmed our patients' perceptions that their recovery has been incomplete. Many patients feel that they are not as capable, mentally or physically, as they were before their acute episode of TTP. (5) Finally, the meetings have provided a resource for education not only of our patients and their families but also for our students. Many students have participated in the projects of The Oklahoma TTP Registry<sup>3</sup> and these meetings provide a forum for presentation of their data. Presentations to the actual subjects of the research can be daunting for students, but it provides a valuable lesson for appreciating patients as peers.

The combined experiences of the Oklahoma and Kansas City TTP Support Groups emphasize the unmet need provided by these opportunities for health professionals and patients to meet, to share their experiences, and to learn more about TTP.

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