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EGPA association in Italy connecting patients and doctors, goal is to serve 1,000 patients nationwide

By John Fries

Dr. Marco Folci, a clinical immunologist in Milan, Italy, is one of several medical professionals who founded Italy's first professional association dedicated to the study and treatment of vasculitis, with an emphasis on EGPA.

Through the Associazione Pazienti della Sindrome di Churg Strauss (APACS), established in 2016, Dr. Folci and his colleagues are working on a number of initiatives, including building an Italian registry, connecting patients, centers and specialists, raising funds to stimulate independent research, and producing informational materials.

"Based on epidemiological studies," Dr. Folci said, "We estimate that there are 1,000 vasculitis patients in Italy. But there are very few vasculitis specialists in Italy and there was no real way for patients to interact with and support each other. We created APACS with the aim of improving diagnosis and patient support by fostering research, grouping Italian patients and connecting specialists," he said.

APACS' goal is to reach every patient in our country. "We started to develop a collaboration with the ERN RITA (European reference network on rare diseases) and we are waiting for the response of the board," said Dr. Folci. "Our plan is to work with them to improve awareness in Europe about vasculitides and connect Italian EGPA patients with other European patients, since there aren't any other EGPA associations."

Dr. Folci first had the idea to create APACS in early 2016. After conferring with one of his colleagues at Milan's Niguarda Hospital and connecting with several members of the EGPA group on Facebook, Dr. Folci began developing the association. By later that year the organization was registered and its website was launched.

The organization's structure includes an administrative board composed of nine patients that changes every year. In addition, there is a scientific board composed of specialists, mainly clinical immunologists and nephrologists, with expertise in treating EGPA in addition to performing research on vasculitides.

"At the moment, I'm one of five doctors" he said. "Every staff member is a volunteer. We have about 100 patients associated with us at the moment."

Last year, APACS held its first two meetings. At the first, near Milan, the organization and its mission were introduced to medical professionals the general public. The second meeting, a few

months later in Florence, provided opportunities for patients to learn more about how APACS would benefit them, and to interact with doctors. Dr. Folci said he was pleased with the turnout.

This year, he contacted the VF. “We believe that our mission is in agreement with Vasculitis Foundation, so I suggested that we join together in the effort and grow it over the geographic boundaries,” said Dr. Folci.

The association’s website is at <https://apacs-egpa.org/>.