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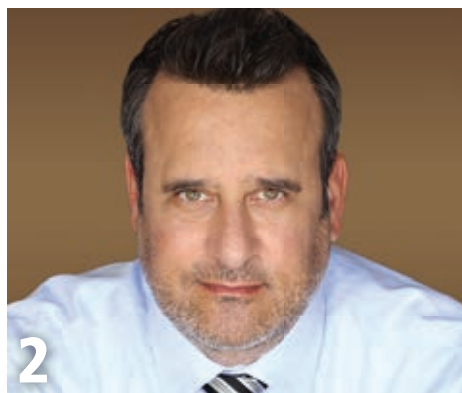
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Photos: (Cover, Top) Laura King, (Cover Inset) Benjamin King, (Center) Bill Branson, (Bottom) Pixabay

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Photo: Bill Branson

Social media brought together Arturo Porzecanski (left), who has a rare disease called systemic capillary leak syndrome, and researcher Dr. Kirk Druey of the National Institute of Allergy and Infectious Diseases. Together, they have expanded clinical knowledge about the condition.

Patient *Power!*

Thanks to the Internet, the “crowdsourcing” of disease information among patients and doctors is becoming a valuable lifeline around the globe. For patients with serious rare diseases, crowdsourcing can mean the difference between life and death.

“Indispensable” is the way NIH researcher Dr. Kirk Druey describes the actions taken by one of his research patients in spreading awareness of a deadly but very rare disease.

Ten years ago, systemic capillary leak syndrome (SCLS) almost took the life of then-56-year-old economist and American University professor Arturo Porzecanski. Parts of his vascular system suddenly leaked out plasma into other parts of his body. In trying to save him before his organs could fail, doctors flooded his system with too much replacement fluid that damaged his leg and arm muscles.

When the attack occurred, Porzecanski and most doctors knew nothing about SCLS. Realizing that another bout of the disease would probably kill him, Porzecanski set out to discover more about SCLS and any other patients who had experienced it.

Through his tenacity and smart use of the Internet, Porzecanski was not only able to find information on new treatments but also identify other patients seeking help in the United States and across the globe. He set up an SCLS community group on a social website

called RareShare (www.raeshare.org). Patients, their loved ones, and health care professionals were sharing contacts, treatment information, and the latest research.

The NIH Connection

In 2008, having built up a network of patients and front-line physicians who could provide medical histories and blood and tissue samples needed to carry out research on SCLS, Porzecanski sought out investigators at NIH's National Institute of Allergy and Infectious Diseases (NIAID). With research already under way on other, related vascular diseases, NIAID's Druey made use of Porzecanski's virtual community to enable a research protocol on SCLS. For a rare disease that has fewer than 1,000 known cases, to recruit patients and their doctors to collaborate with researchers is very difficult yet crucial to eventual success.

"Arturo's efforts were indispensable," says Druey. "And we now have the largest registry of patients for that disease in the world."

Through Porzecanski's efforts on RareShare, he quickly became the go-to patient resource for those with SCLS. He also helped get blood samples from patients to assist Druey and his colleagues in their research at NIH.

"Arturo came to NIH as an inpatient and stayed several days in the Clinical Center hospital here in Bethesda," Maryland, says Druey.

Porzecanski also came to NIH to show Druey and his colleagues all of the research he had put together on SCLS—to pass along his knowledge in the hope that it could help speed along life-saving information to others.

Some 40 SCLS patients and their physicians have provided Druey with blood and tissue samples, or at least medical histories, to further knowledge of the rare disease. He has already published 10 research articles that shed more light on SCLS, with more papers in the pipeline.

Porzecanski has also helped spread the word to SCLS patients that French researchers have developed a treatment of high-dose intravenous immunoglobulins (IVIg) that can be effective in stopping SCLS and lengthening the lives of patients—including Porzecanski.

Porzecanski and Druey have made quite a team in their efforts to understand and defeat SCLS.

"I'm fully invested in this research," says Druey. "I feel this is something I owe to these patients."



Photo: Kathleen Cravedi

▲ Porzecanski and Druey have worked together since 2008 to help connect patients with systemic capillary leak syndrome, a rare disease that has only about 100 known cases. They aim to spread life-saving information to those with the disease.

In fact, Druey and his colleagues have already applied for a grant to help fund a gathering of scientists from across the globe who are now studying SCLS.

Porzecanski couldn't be happier that such "patient power" efforts will help SCLS patients who otherwise would be without hope.

Find Out More

- ✓ **MedlinePlus — Rare Diseases:**
www.nlm.nih.gov/medlineplus/rarediseases.html
- ✓ **Genetic and Rare Diseases (GARD) Information Center:**
rarediseases.info.nih.gov
- ✓ **How to Find a Disease Specialist:**
rarediseases.info.nih.gov/resources/pages/25/how-to-find-a-disease-specialist
- ✓ **Rare Diseases Clinical Research Network:**
www.ncats.nih.gov/rdcrn