

Rare diseases, special care

Tom Westrich, BPharm, and Centric Health Resources specialize in patients with orphan diseases

Pemphigus. Alpha 1-antitrypsin deficiency. Hemophilia. Most pharmacists will seldom, if ever, have to counsel patients with orphan diseases such as these. But Tom Westrich, BPharm, Vice President of Pharmacy Services for Centric Health Resources in St. Louis, MO, and his colleagues deal with these disorders every day.

Orphan diseases are officially defined by the U.S. Orphan Drug Act (ODA) of 1982 as those that affect fewer than 200,000 people; more than 5,000 such diseases exist. These include generally familiar diseases such as Huntington's disease, amyotrophic lateral sclerosis (ALS, or Lou Gehrig's disease), and muscular dystrophy, as well as far more obscure conditions such as Kabuki syndrome and geographic tongue. Since the passage of ODA, more than 200 drugs and biological products have been approved for these rare diseases.

Centric Health Resources, based in Chesterfield, MO, helps manage the care of patients throughout the country with some of these rare diseases, specializing in alpha 1-antitrypsin deficiency, pemphigus, and hemophilia (with cystic fibrosis soon to be added). "Centric's mission is to improve the lives of people with rare, orphan, and chronic disorders," Westrich told *Pharmacy Today*. "Working with physicians, our approach integrates the delivery of specialized pharmacy services with comprehensive, patient-centered health management services and patient advocacy. It's a multidisciplinary approach that involves patients, physicians, nurses, and any other caregivers."

Cross-country care from St. Louis

A multidisciplinary approach to care is essential to Centric's strategy, Westrich said. Describing its patient care approach in detail, he explained, "All patients are contacted by a multidisciplinary team when they initiate service with us. They speak to our intake team to discuss the financial implications of their treatment and find out what services are available. They speak to our nursing

team to discuss options for receiving the prescribed therapies, such as outpatient care, home care, and so on. Our pharmacists counsel them regarding typical drug-related issues—dosage, possible adverse effects, drug interactions, storage, pharmacy phone number, the refill process—but also about any of their other medications and concerns. We encourage them to call us if they have any questions or suspect that they are having problems with the drug therapy."

Centric's pharmacists contact about 200 patients and their health care providers every day "to discuss therapy, adherence, and any necessary services," Westrich said. These phone calls—all counseling is done via telephone—can last anywhere from a

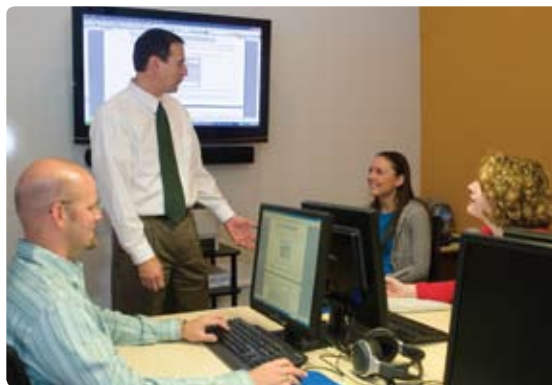
few minutes to an hour depending on the patient's response to therapy and any new issues. To provide this care, Centric employs 6 registered pharmacists, 16 licensed pharmacy technicians, 7 registered nurses, 26 reimbursement specialists, and 5 information technology specialists in their home office; supporting this staff is a nationwide network of more than 250 nurses and 1,000 home health agencies. "For some of our programs, we also partner with patient advocacy groups that have peer coaches to provide support and assistance to patients, helping them deal with the challenges they face," Westrich added.

As Vice President of Pharmacy Services, Westrich coordinates this network of patient care experts.

"I'm responsible for day-to-day operations ... including patient services, inventory control, quality control, training, policy and procedure development, staffing, and regulatory compliance. I also work closely with our manufacturer clients' quality control staff to ensure that their products are handled appropriately through our distribution channels," he told *Today*.

Opportunity lived next door

The chain of events that led Westrich to his position with Centric stretches back to a childhood neighbor who was a pharmacist in his hometown of Cape Girardeau, MO. Another coincidence influenced his eventual choice of careers. "One day before I was



Tom Westrich, BPharm, Vice President of Pharmacy Services, leads a pharmacy training session with Doug Carlson, Quality Assurance Director; Lindsay Hunter, Customer Service; and Tina Pheasant, Information Technology Application Specialist.



Centric

to meet with my high school counselor to discuss my career ideas, the registrar from the St. Louis College of Pharmacy visited to discuss the curriculum and the profession,” Westrich explained. “I initially had thoughts of going on to medical school. . . . When I graduated, an additional pharmacist position was added at a local hospital, so I stayed there, providing education services to newly diagnosed patients with diabetes.”

Westrich had his first experience with chronic conditions as a specialty I.V. compounding pharmacist at the Jewish Hospital of St. Louis (now Barnes–Jewish Hospital). “The hospital started a home infusion program, subcontracting for services with a local home infusion company, and I managed clinical patient care,” he said. This program evolved into an independent home infusion company, American Home Therapies, with Westrich as

Vice President of Clinical Services. After a series of mergers and acquisitions in the mid-1990s, Westrich became National Director of Quality Improvement for Coram Healthcare in 1995.

At Coram, Westrich gained experience managing a large patient care network. His responsibilities included developing and implementing a risk management program, helping Coram through Joint Commission accreditation and reaccreditation, and overseeing participation in a CDC-sponsored study of home I.V. therapy. The results of the latter study helped Coram implement an intervention procedure that reduced emergency department

visits or hospitalizations due to suspected catheter infections from 72% if the patient called the physician to 18%. Westrich also helped develop the Corameters Program, “an interactive outcomes database of patient information, including utilization, disease states, costs, length of therapy, and other criteria,” he said.

“My time in this position [with Coram] allowed me to really appreciate the impact that good informatics can have in operationalizing performance, patient care, and outcomes,” Westrich said. “I use the knowledge from my clinical practice, management, quality improvement and risk management, informatics and systems, regulatory, and operational experience to establish the processes used by Centric today.” The experiences that help Westrich in his daily responsibilities also reach beyond his professional life. “My true passion is

coaching girls’ club volleyball,” he told *Today*. “I enjoy the teaching aspect, helping players improve. I have a similar philosophy as a manager, in that my responsibility is to encourage the staff and help them improve their performance and teamwork.”

“I THINK ALL PATIENTS can benefit from additional counseling and education regarding their medication.”

Unique care for unique patients

Westrich’s experience has also led him to value the patient services pharmacists can offer. “I think all patients can benefit from additional counseling and education regarding their medication regimen,” Westrich said. “Most community and mail-order phar-

“BPS certification assures other member of the health care team that our pharmacist partners are giving our patients the best, most up-to-date information.”

—Sandra R. Edwardson, PhD, RN, Professor, School of Nursing, University of Minnesota, MN

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macies provide patients with written medication information sheets, but patients using specialty pharmaceuticals such as newer biotech drugs, those with narrow therapeutic windows, or those with significant possible adverse effects especially need personal interventional counseling.”

Centric offers these counseling services to a unique patient population, negotiating exclusive distribution partnerships with some pharmaceutical manufacturers. Having experienced both sides of these arrangements, “I can appreciate how restricting access can significantly benefit patient communities, especially the small communities with orphan and ultra-orphan conditions,” Westrich explained to *Today*. One benefit is that direct distribution ensures that patients who need specialty drugs have access to them. “Many of the pharmaceutical products used to treat these conditions are in limited supply,” Westrich said, adding that he has seen “artificial shortages in that there was enough product to serve the patients needing the medication, but it wasn’t accessible to the pharmacies that needed it, because it was sitting on some other pharmacy’s shelves, unused.”

Westrich also believes that the direct distribution model allows a greater opportunity for aggregating patient data by bringing the small patient populations under a single umbrella. “We are able to work with the manufacturers, the patient communities, and the physicians treating these patients to share data and find opportunities to improve the services provided and the patient experience,” he said. Additionally, rare diseases are often difficult to treat because many physicians may be unfamiliar with

their signs and symptoms. “The average time to correctly diagnose a patient with alpha 1-antitrypsin deficiency is 7 to 8 years because they’re typically misdiagnosed with chronic obstructive pulmonary disease, asthma, or emphysema before they’re correctly tested for this protein deficiency,” Westrich explained. “A partnership between an exclusive source pharmacy, the patient community, and the manufacturer can help identify ways to communicate information related to a rare condition.”

Centric’s unique position allows it to significantly improve patients’ quality of life, Westrich said. “We have had patients lose their homes because of fire, and our team has put together donation drives to gather clothing and household items. We have worked with many of our patients to coordinate nursing services so they can go on vacations and live a fuller life,” he explained.

Westrich offered one example in particular illustrating the services Centric can offer. “We had one patient who had not been infusing. When we called to talk about it, we discovered that the patient’s condition had progressed to the point where he could not get to his local medical facility, where he had been going for years for infusions, or to the local grocery store,” he said. “We made arrangements with one of the nurses in our network to transition this patient to home infusion and with a local support organization to help with the other issues. Even though we were providing long-distance care, we could use our experience and expertise to help this patient get through a very difficult time.”

—Alex Egervary

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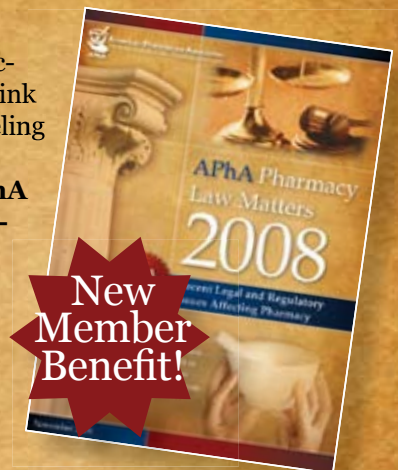
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