

PATHways

November 2010

Infusion nurses' expertise enhanced by annual Replagal® Education Day

People who live with Fabry disease benefit when nurses receive ongoing education about this rare condition and its treatment.

At Bayshore Specialty Rx's annual Replagal Education Day, nurses learn about the latest research developments and best practices for care. Guest speakers share their expertise about Fabry disease, a rare genetic condition caused by a faulty or missing enzyme in the body. It affects a person's ability to metabolize lipids, which leads them to build up to harmful levels in the kidneys, eyes, cardiovascular system and autonomic nervous system.

The theme of the most recent education day was "Fabry Disease and the Caregiver." More than 25 of Bayshore's primary care nurses from across Canada attended the event in Halifax. Their enhanced knowledge offers reassurance to patients, especially those new to Replagal.

"They may be initiating therapy for the first time at home, or they may be transitioning from a different drug, a different care setting or a different provider," says Tammy Ash, Bayshore's Pharmaceutical Program Manager. "The fact that nurses are very familiar with the treatment instills confidence."

The most recent session featured both external and internal speakers. Dr. Michael West, Principal Investigator for the Canadian Fabry Disease Initiative (CFDI) study of Replagal, provided an overview of the therapy and a presentation on CFDI. Kaye LeMoine, RN and National Coordinator for the CFDI, presented a Replagal case study. Ryan Deveau, who lives with Fabry disease, spoke about his personal experiences (see page 4), and Dr. Gordon Butler talked about the psychological effects of living with a chronic illness.

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BAYSHORE SPECIALTY RX: PROVIDING REPLAGAL INFUSIONS TO FABRY PATIENTS

Replagal home and clinic infusion services are provided by Bayshore Specialty Rx, which brings together three different core services into an integrated, one-stop process that supports the unique needs of each client.

We provide infusion services in the home and through our network of more than 20 community care clinics across Canada, offering a comfortable alternative to the traditional hospital setting. Our infusion pharmacy specializes in the preparation, storage and delivery of infusion, injection and specialty medications, including related supplies and equipment. We also provide support services to pharmaceutical companies, so they can effectively market their products and ensure they are administered in a safe, timely manner to patients. The result is customized solutions for clients and better overall coordination of care for patients.

Bayshore Specialty Rx is a subsidiary of Bayshore Home Health, the country's largest provider of home and community health care services, with more than 50 home care offices and 8,000 employees.

For more information, please visit www.bayshore.ca.

BAYSHORE REPLAGAL NURSE CELEBRATION DAY

More than 40 of Bayshore's Specialty Rx's primary care nurses and Fabry disease experts from across Canada attended the company's Replagal Nurse Celebration Day, held in October.

Education Day (continued)

Bayshore had several speakers at the sessions including a project leader from the company's pharmaceutical support services department, who discussed adverse events and working with partner organizations, and its director of pharmacy, who talked about educating patients on the safe storage and handling of Replagal. Infusion nurses Debbie MacKenzie, Carrie Burton and Christina Vokey shared experiences of working with patients, including how they handle challenging situations. Their discussion instilled confidence in newer nurses, who felt inspired and learned innovative ideas for their own practice.

Nurses who attended the event provided positive feedback on the practical and applicable information that was shared. "Attending the Replagal Education Day, ensures that our nurses are provided with current, evidence-based care practices," says Ash. "They can then better meet the specific needs of our Fabry patients, now and in the future."

For more information, please contact tash@bayshore.ca

"For several months now, I have been fortunate to receive enzyme replacement therapy at home. I would like to express my appreciation for this treatment which is provided in my home by a very competent and caring nurse who really knows how to listen. Her presence is always valued and most comforting. Heartfelt thanks for your excellent service."

– Lise Rivard
Montreal, Quebec



The Replagal HomePATH infusion program



The Replagal HomePATH (Patient Assisted Team Health) program is a clinical case management program that manages all aspects of a Fabry patient's Replagal infusion therapy and associated care. It was developed by Canadian home and community health care provider Bayshore Home Health, and introduced in 2004. The program has been delivered by Bayshore Home Health's subsidiary Bayshore Specialty Rx since 2007.

The program is available at no charge to Fabry patients who receive Replagal infusions and is fully funded by Shire Human Genetic Therapies Canada, the manufacturer of Replagal. Treatment can be arranged through a physician, nurse or genetic counsellor at a patient's treatment centre.

Replagal is a form of enzyme replacement therapy that Fabry patients may be prescribed by their physician specialists. The treatment consists of a 40-minute infusion every two weeks. Through the HomePATH program, patients receive treatment in the privacy of their own homes, at a time that is convenient for them. Each Fabry patient is assigned a clinical case manager who oversees the entire process.

The HomePATH program encourages Fabry patients to become involved in the development of their care plan and to use their health care team to achieve optimum health outcomes. Specially trained nurses work closely with patients to develop a schedule and care plan tailored to their needs.

For more information about the Replagal HomePATH Program, please call Bayshore Specialty Rx at 1-800-668-9490 Ext. 320.

PROTECTING YOUR PRIVACY

Bayshore Specialty Rx and Bayshore Home Health believe all clients have the right to privacy and confidentiality of information.

As a result, we are committed to ensuring the confidentiality and protection of personal information in our possession. As required by law and professional standards, we collect, use and disclose personal information for the sole purpose of providing our clients with high quality health care services. We are committed to sound information management and current privacy legislation.

Benefits of the Replagal HomePATH Program

- Personal Replagal clinical case manager
- Evening and weekend scheduling options
- A consistent primary infusion nurse
- Direct-to-patient drug and supply deliveries
- Regular physician updates
- Patient satisfaction surveys
- Individualized patient follow-ups

Starting the Replagal HomePATH Program is easy as 1-2-3

1. Once your physician has decided to put you on enzyme replacement therapy, a completed medical directive is faxed to the Replagal HomePATH service department.
2. Your Replagal case manager will contact you at the phone number of your choice, to explain the program, arrange drug and supply deliveries and schedule your first HomePATH visit.
3. A highly experienced infusion nurse, with specialized training in the use of Replagal, is assigned to you. This nurse will work with you to develop your care plan and infusion schedule.

Caring for the whole person: The psychological impact of chronic illness

The physical symptoms of a chronic condition such as Fabry disease can have an enormous impact on a person's life, but they aren't the whole story. Emotional and psychological well-being can also be affected, presenting additional challenges to both patients and caregivers.

"Early detection of problems with quality of life, depression or anxiety is really critical in terms of treatment," says Dr. Gordon Butler, a psychologist at Queen Elizabeth II Health Sciences Centre in Halifax. "The earlier you catch [the issues], the better, and caregivers are often in a good position to note changes."

When caregivers are aware of potential issues, they can help address them. For example, anxious patients may feel better if they have more information about their treatment. "Ask the patient what helps, or what suggestions they have, if they're having trouble coping," says Dr. Butler.

Patients also benefit from encouragement, acknowledgement of difficulties they face, and recognition of their accomplishments – many people with Fabry disease work, attend school and have busy social lives despite the challenges of their condition.

Caregivers can also play a major role in boosting patients' comfort level with their treatment. Ryan Deveau, a Replagal patient since 2007, credits the support he received from his Bayshore Specialty Rx nurse for helping him adjust to Replagal infusions for Fabry disease.

"My nurse was very confident, and I felt like she was in control of the situation from start to finish. I never had to worry about what was going on. She would explain to me what was happening. Knowing that made me feel better about the whole process," he explains.

Deveau's spouse, Stephanie, now helps him with the infusions, but he is still deeply grateful for the early support. "I want to thank my Bayshore nurse from the bottom of my heart. I will never be able to completely explain how much they have helped me," he says.



Replagal patient Ryan Deveau, with his wife Stephanie, credits the support he received from his Bayshore Specialty Rx nurse for helping him adjust to Replagal infusions for Fabry disease.

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