

Treatment solutions for Fabry disease patients

PATHways

May 2008

Canadian Fabry Disease Initiative is enhancing knowledge and treatment of the disease

The Canadian Fabry Disease Initiative (CFDI) is progressing smoothly in its second year of operation. The project is a collaborative effort between Canada's federal and provincial governments and the pharmaceutical industry to fund enzyme replacement therapy (ERT) for the next several years in the form of a research study that evaluates patient outcomes.

A key goal of the study is to create a national database of long-term data on Fabry patients, including information from clinic visits and test results. This information will allow a team of Canadian specialists to assess how effective ERT is in preventing, controlling and reversing the clinical symptoms of Fabry disease. It will also compare the effectiveness of the two available ERTs – Replagal® and Fabrazyme®.

There are currently 175 patients enrolled in the CFDI across Canada. Forty-four of the patients reside in Ontario, which has the largest population of Fabry patients outside of Nova Scotia. The majority of Ontario patients are monitored by Dr. Joe Clarke and his teams at the University Health Network and Hospital for Sick Children in Toronto. There are also satellite sites across Ontario – including London, Hamilton, Kingston and Ottawa – participating in the project. The CFDI is coordinated in each province through a coordinating centre that oversees all drug delivery and data collection.

Fabry patients who have consented to participate in the CFDI are making a huge contribution towards the knowledge of Fabry disease and the current treatments available. Patients can help to ensure



Medical specialists involved in the Canadian Fabry Disease Initiative, from left to right: Tracy Heeney (Ontario Co-ordinator for the CFDI), Laura Moldovan (Clinical Research Analyst), Dr. Joe Clarke (Principal Investigator for the CFDI for Ontario), Carolina Azcona (Genetic Counsellor) and Linda Vorano (Administrative Assistant).

Bayshore
Specialty Rx

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Replagal® infusion services provider scores high marks in patient satisfaction survey

Replagal infusion services provider Bayshore Specialty Rx earned high marks in a recent patient satisfaction survey. It scored the highest possible rating from more than 80% of respondents in 9 of 12 areas of service performance.

“The survey gives us a better understanding of how well we are meeting our patients’ home infusion expectations,” says Mani Rahman, the company’s Replagal Program Manager.

The survey asked patients to rate their satisfaction with Bayshore in key service performance areas. Some of the areas in which the company achieved the highest possible “strongly agree” ratings were as follows:

- 95% > Infusion nurse treats me with courtesy and respect.
- 89% > Staff who provide my care demonstrate the required knowledge, skills and competence.
- 89% > I receive updated and essential information that I require in a language I understand.
- 89% > Bayshore meets my expectations as my health care provider.

89% > Infusion nurse is usually the same person.

84% > Staff treat me with courtesy and respect.

84% > Staff are capable and reliable in scheduling my infusions.

83% > I would recommend Bayshore to my friends and family.

Respondents also provided a number of enlightening comments about the importance that home infusions play in their lives, including:

“Infusions are so much better in my home instead of a hospital.”

“In doing home infusions, I find that I travel less, allowing me to go to work.”

For more information, please contact mrahman@bayshore.ca.



Bayshore Specialty Rx staff who manage the company’s Replagal infusion program. From left: Suzanne Nagy (Director, Pharmaceutical Services), Mani Rahman (Replagal Program Manager) and Nicole Brown (Senior Client Service Specialist).

Replagal infusion services now delivered through a new company – Bayshore Specialty Rx



The Replagal home and clinic infusion services previously offered under the Bayshore Home Health brand are now being delivered through a new affiliated company, Bayshore Specialty Rx. The company was formed so that Bayshore can deliver its pharmaceutical services through a single entity that specializes in this area. Its three core offerings are: Infusion Services (a network of more than 20 infusion clinics across Canada plus in-home infusions); Pharmacy Services (preparation, storage and delivery of intravenous drugs and related supplies and equipment); and Pharmaceutical Products Support Services (product and patient support services for pharmaceutical companies).

Bayshore Home Health is the country’s largest provider of home and community health care services, with more than 40 home care offices and 7,000 employees.

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

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 July 2004.

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 are 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. 321.

► Protecting your privacy

Bayshore Specialty Rx and Bayshore Home Health believe all clients have a 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.

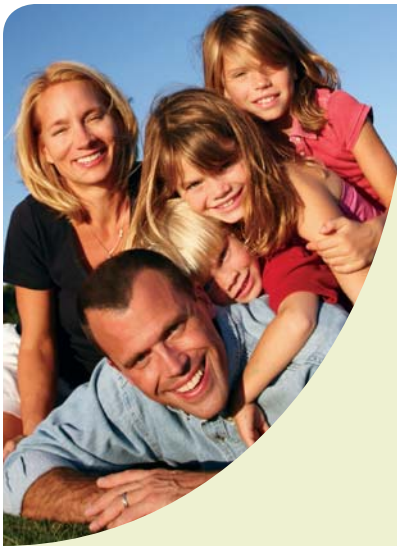
Benefits of the Replagal HomePATH Program

- 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.



Fabry Disease: What does it mean to family members?

By *Carolina Azcona* MSc, CGC, CCGC Genetic Counsellor, University Health Network, Toronto

Fabry disease is a rare genetic disorder in which the cells of the body cannot break down a specific lipid called globotriaosylceramide (commonly known as Gb3). Over time, Gb3 accumulates and leads to damage within organs including the heart, kidneys and brain.

Fabry disease is a hereditary condition passed from parent to child. Previously it was believed that the disease only affected males but we now know that many women also show symptoms although often in a milder form. Given its hereditary nature, the disease can affect several members of the same family. But since the presenting symptoms and signs tend to be vague, it is often misdiagnosed or missed altogether. Early diagnosis and treatment can greatly alter the course of the disease.

Once a diagnosis is made in a family, it is crucial for healthcare professionals to ensure that a detailed family history is taken to determine which family members are at risk. Men with Fabry disease can only pass the condition to their daughters but women can pass the condition to both males and females. At-risk family members should be encouraged to seek out specialists trained in genetics for a thorough discussion of Fabry disease and subsequent genetic testing, regardless of whether they have symptoms.

Due to their expertise, genetic counsellors or metabolic nurses can explain complex genetic information in simple, understandable language. They can also facilitate genetic testing and appropriate referrals. If you think you or a family member may have Fabry disease, speak to your family doctor or contact your nearest genetics centre. They can direct you to a clinic with expertise in Fabry disease. With currently available enzyme treatment, early diagnosis is the key.

For more information, please contact carolina.azcona@uhn.on.ca

What our clients say

Bayshore has been so helpful and accommodating to my needs. Being a student, it is difficult for me to take time off to get my treatments. Bayshore provided me with a nurse who is willing to work by my schedule. This was very important to me because it allowed me to concentrate on my schooling instead of worrying about scheduling time for my treatments. I am truly satisfied with their response and attention to my inquiries. Their service is prompt and effective, and they are always willing to go the extra mile to be of service. I commend them and am grateful that I can rely on them.

— *Sabrina Sgroi*
Waterloo, Ontario

CFDI *(continued from cover)*

the success of the initiative by avoiding missed infusions, completing scheduled tests and making sure their health care team is aware of any unusual symptoms experienced after infusions.

For more information about the CFDI, please call 416-586-4800, Ext. 4229, or visit www.medscinet.net/CFD.

Useful
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Replagal
HomePATH
program

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