

What is ENFit?®

DISCUSSING ENTERAL CHANGES



As all feeding tube (enteral) connectors are changing, we want to make sure you are confident in how this impacts your child's care. PHS recently hosted a Facebook Live

broadcast to discuss the impacted products, timeline for changes, what the new connections look like, cover the resources we've created, and answer questions.

Learn more about our resources and see the video at:
PediatricHomeService.com/blog/enfit-changes-enteral-connectors

New Sibling Support Group

12 WEEK PROGRAM STARTS ON FEBRUARY 14



Our clinical social worker Monica Handlos will be kicking off a new session of the support program for siblings of children with medical complexities on February 14! There

is space for six children ages 6-11 who would benefit from the opportunity to process their thoughts, work through their feelings, and express themselves in a group setting.

Learn more about the program and fill out an interest form at PHSSiblingSupport.com



2800 Cleveland Avenue North
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Be sure to visit the Thrive blog at
PediatricHomeService.com/blog

INSIDE THIS ISSUE

Curiosity and Positivity Fuel Joe's Future

PLUS:

Marriage with a medically complex child, Understanding changes to enteral connectors, and a look at enzyme replacement therapy



Thriving at Home

WEEKLY INFUSIONS ARE JUST ONE PART OF JOE'S BUSY SCHEDULE



Every Thursday, infusion nurse Kate Joseph spends her afternoon administering enzyme replacement therapy

for 12 year old Joe. And because he's able to get this infusion at home, Joe barely misses any school - a big change from their experience when he was first diagnosed with Morquio Syndrome. When he was 5 years old, Joe and his mom travelled to Chicago weekly for him to receive treatment as part of a study.

Thanks to weekly infusion treatments, Joe is growing and thriving as he maintains a schedule filled with Lego Robotics League, homework, painting, and Dungeons & Dragons.

"I wrote our Christmas card in October and said he'd grown over an inch since starting treatment, and I had to go back because he had grown another inch by December," said his mom Karin.

Joe will need this therapy his entire life, but that won't slow this boy who wants to grow up to be "a lot of things."

To learn more about Joe, visit [PediatricHomeService.com/blog/joe-enzyme-replacement-therapy](https://www.PediatricHomeService.com/blog/joe-enzyme-replacement-therapy)



Marriage With A Complex Child

BLOG SERIES DISCUSSES ASSOCIATED CHALLENGES

Perhaps one of the biggest changes in a married couple's relationship happens when a child is born. bringing an abundance of love along with new challenges. But how does that change when the child has medical complexities?

We were curious to learn how marriages are affected by children who come home with extensive medical needs, and found ourselves coming up empty handed when we went in search of resources - so we talked to the people who know its impact firsthand: the parents of these kiddos.

In the first article of our three part series, we explore what aspects of marriage are impacted when raising a child with medical complexities - ranging from social life changes to financial burden.

See our first of three posts on this topic at: [PediatricHomeService.com/blog/marriage-medically-complex](https://www.PediatricHomeService.com/blog/marriage-medically-complex)



A New Year To Advocate A DAY IN THE LIFE AT THE CAPITOL

As a new legislative session kicks off, PHS is ready to ensure the kids we take care of each day have access to the best health care possible - and that they continue to receive that care at home.

Have you wondered what goes into helping legislation move forward in the House and Senate? We spent a day tagging along with Bill Amberg, Government Relations Counsel at PHS, to get a glimpse into the conversations, hearings, and meetings that help tell your stories and relay just how important care at home is for our patients.

If you're interested in being involved, we would love to hear from you. Give us a call to learn more and we can talk about all the different ways you can share a day in your life with your local representative.

Follow a day in Bill's life at: [PediatricHomeService.com/blog/2017-legislation](https://www.PediatricHomeService.com/blog/2017-legislation)



Message From Our Medical Director

ENZYME REPLACEMENT THERAPY

Of the more than 40 identified lysosomal diseases, PHS has provided infusion services for patients with five of these disorders - Pompe disease, Gaucher disease, Fabry disease, Morquio Type A, and Hunter syndrome.

For children and their families living with enzyme replacement therapy (ERT), this treatment provides hope for improvement of symptoms as well as increased quality and quantity of life.

Through ERT, a new combination of manufactured enzymes replace the insufficient or defective enzyme that normally reside within the cell. Patients require weekly infusions to obtain these necessary enzymes.

Read more of Dr. Maynard's article on enzyme replacement therapy at [PediatricHomeService.com/blog/enzyme-replacement-therapy](https://www.PediatricHomeService.com/blog/enzyme-replacement-therapy)

Pediatric Home Service can serve you **24 hours a day, 365 days a year.**
Call **651-642-1825** or visit **[PediatricHomeService.com](https://www.PediatricHomeService.com)**.