

Living and Thriving: Meet Dawn Bowles! Delta Dental Program Participant

Many women find that receiving a bleeding disorder diagnosis can be a long and curvy road. Dawn Bowles is no stranger to that journey. She vividly remembers bleeding profusely into a towel after recovering from a tonsillectomy at 8 years old. Her doctors could not identify the source, and her family, burdened with other bills, could not afford to follow up with additional testing. Although she had two uneventful births, Dawn suffered for many decades with heavy periods before she was finally diagnosed with Factor XIII deficiency. A second bleeding disorder diagnosis came in a most unusual way.

In early 2006, Dawn went for a routine physical with her primary care physician. At that time, they found a heart murmur. Further testing revealed major blockages and Dawn faced a triple bi-pass and mitral valve replacement. Although they treated her Factor XIII deficiency she experienced significant post-operative bleeding complications and was subsequently diagnosed with vWD.

In 2015, by chance, Dawn learned about the Hemophilia Foundation of Michigan and the Delta Dental Program funded through Cascade. She, more than anyone, understands that our teeth are interconnected with our well-being and our health. Periodontal disease and tooth infections had caused Dawn to develop endocarditis, a bacterial heart infection that commonly occurs in people with certain heart conditions.

"I had been so sick with endocarditis. Finding the Delta Dental program was perfect timing because I could get the cleanings and dental work I needed."

Regular dental cleanings help keep periodontal tissue healthy, which is essential to prevent bleeding and tooth loss. But, as Dawn can agree, it also promotes good heart health.

"Your dental program saved my life! I have a lot to smile about!"

Dawn was able to have 6 teeth replaced through the program and plans to have regular periodontal cleanings with her dentist. "I wouldn't want anyone else to go through what I went through. This program is wonderful." Dawn states, as she smiles her beautiful new smile.



"I had been so sick with endocarditis. Finding the Delta Dental program was perfect timing because I could get the cleanings and dental work I needed."

Cascade Can Get You the Resources You Need

If You Need a Little Help, Give Us a Call!

- ✓ **Community resources** to address needs such as transportation, housing, financial needs, career planning, employment, or dental programs.
- ✓ Information about **public benefit programs** such as SSI/SSDI, Medicaid and CSHCS including assistance with applications
- ✓ Information and assistance **navigating health insurance** systems
- ✓ Referrals to programs for **social support and networking** with others in the bleeding disorders community

Call 734-996-3300 and ask for Colleen Joiner, LMSW or Debbie Whelan, LMSW

All services are confidential and provided in coordination with your treatment center when applicable.



517 West William Street
Ann Arbor, MI 48103
Hours: M-F 9:00 am - 5:00 pm
Available for after hours emergencies
Phone: 734-996-3300
800-996-2575
Fax: 734-996-5566
www.CascadeHC.org
info@CascadeHC.org



Cascade Hemophilia Consortium

Letter From Cascade Social Worker Debbie Whelan



Dear Readers,

This month's issue highlights some of the resources available to members of the bleeding disorders community. We recognize the high costs of bleeding disorder treatment can create financial stress, and the challenges of navigating insurance coverage are many. Local and national resources are available to help you meet those challenges. We hope you find them helpful. If you have questions, need more information, or don't see the resource you're looking for here, calling your HTC or Cascade social worker is a great place to start.

Debbie

Debbie Whelan, LMSW

Cascade...
A Trusted Partner in
Your Circle of Care

Notice: If you speak English, language assistance services, free of charge, are available to you. Call 1-800-996-2575.
ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-800-996-2575.
(1-800-996-2575) पूरे: इस सेवा को आप, बिना किसी शुल्क के, प्राप्त कर सकते हैं। हमारे कर्मचारियों को 1-800-996-2575 पर कॉल करें।

Does a Lack of Dental Insurance Bring You Down? There May be Help!

Cascade provides funding to hemophilia foundations in our region to administer a high quality Delta Dental program for members of the bleeding disorder community.

Do You Qualify?

- ✓ You have a bleeding disorder or are a symptomatic carrier (Family members without a bleeding disorder are also eligible in Ohio only)
- ✓ You have no dental insurance or inadequate dental insurance (in special cases)
- ✓ You are a resident of Michigan, Ohio or Indiana
- ✓ You agree to USE the insurance

Low cost or no costs premiums and requirements vary in each state.

For More Information or to Apply

Michigan Residents

Call the Hemophilia Foundation of Michigan at 734-544-0015 or go to www.HFMich.org/deltadental to download applications.

Ohio Residents

Call Randi Clites at the Ohio Dental Program at 330-730-1259 or e-mail randi@nohf.org.

Indiana Residents

Call Angel Couch at the Hemophilia of Indiana, Inc. at 317-570-0039.



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Executive Director, Cascade

Emergency Financial Assistance

Michigan Residents

Hemophilia Foundation of Michigan – Michigan residents only

Please call Lisa Clothier, LLMSW at 734-544-0015. She coordinates assistance with your hemophilia treatment center.

Area Agencies on Aging (AAA)

Assists individuals age 60 and older with coordination of services including meals-on-wheels, transportation and other supportive services. The AAAs also offer prescription drug financial assistance, food programs and end-of-life assistance. Services are provided primarily through agencies that contract with the AAAs. To find a local office in your area, please call Michigan Office of Services to the Aging, 517-373-8230

Ohio Residents

Ohio Chapter Assistance

Please contact your local chapter listed below for financial assistance.

Guidelines vary with each chapter.

Indiana Residents

Hemophilia of Indiana, Inc. – Indiana residents only

Please call HOII at 317-570-0039 or 800-241-2873 for assistance.

National Programs

Hemophilia Federation of America

Helping Hands Program: Provides emergency financial assistance to individuals with a bleeding disorder. A social work referral is required. Please call your HTC or Cascade social worker for assistance.

Colburn/Keenan Foundation

The Colburn-Keenan Foundation's charitable giving programs provides assistance and support to individuals and families impacted by inherited bleeding disorders. The Foundation's individual grants are meant to help individuals and families meet their urgent medical, basic survival, and quality of life needs. To download an application, please go to: <http://www.colkeen.org>. An HTC referral is required.

United Way 211 Help Line

This service directs all residents to local agencies and services throughout your state to meet your specific needs.

Simply dial '211.'



Hemophilia Foundations

Central Ohio Chapter

4400 N High Street, Suite 216

Columbus, OH 43214

Phone: 614-902-3965

Website: www.nhfcentralohio.org

Northern Ohio Hemophilia Foundation

Liberty Plaza

5000 Rockside Rd, Ste 230

Independence, OH 44131

Phone: 216-834-0051

Website: www.nohf.org

Southwestern Ohio Hemophilia Foundation

3131 South Dixie Drive, Suite 103

Moraine, Ohio 45439

Phone: 937-298-8000

Website: www.swohohemophilia.org

Tri-State Bleeding Disorder Foundation

635 W Seventh Street, Suite 407

Cincinnati, OH 45203-1549

Phone: 513-961-4366

Website: www.tsbfd.org

Northwest Ohio Hemophilia Foundation

2121 Hughes Drive

Harris Macintosh Tower, Suite 940

Toledo, OH 43606

Phone: 419-291-5882

Website: www.nwohemophilia.org

Hemophilia of Indiana, Inc. (HOII)

6910 N. Shadeland Ave, Suite 140

Indianapolis, IN 46220

Phone: 317-570-0039

Website: www.hoii.org

Hemophilia Foundation of MI

1921 West Michigan Avenue

Ypsilanti, MI 48197-4816

Phone: 734-544-0015

Website: www.hfmich.org

Social and Support/Programs

Many Hemophilia Treatment Centers and Foundations provide parent support dinners, social events, and other activities available to you and your family.

Ask your Hemophilia Treatment Center staff for more information.

Insurance Co-Pay Assistance Programs

- ✓ Most, if not all, of the programs below do not have any income requirements
- ✓ You must have commercial/private insurance to qualify for these programs (not Medicare or Medicaid)
- ✓ Some programs will pay your co-pays retro-actively (after you have ordered or received your factor product).

Manufacturer	Co-Pay/ Co-Insurance Program	Limit Per Year	Factor Product
Aptevo Therapeutics	855-494-6489	\$12,000	Ixinity
Shire	888-229-8379	\$12,000	Advate, Feiba, Recombinate, Adynovate, Bebulin, Rixubis, Hemophil M, Vonvendi, Obizur
Bayer	800-288-8374	\$12,000	Kogenate, Kovaltry
Biogen	Aprolix: 855-692-5776 Eloctate: 855-693-5628	\$12,000	Aprolix, Eloctate
Bio Products Lab (BPL)	844-427-5872	\$12,000	Coagadex
CSL Behring	800-676-4266	\$12,000	Afstyla, Idelvion, Helixate, Humate P, Monoclate, Mononine
Grifols	844-693-2286	\$6,000 (\$500/mo max)	Alphanate, Alpha-nine
Novo Nordisk	844-668-6732	\$12,000	NovoSeven- NovoEight, Tretten
Octapharma	800-554-4440	\$6,000	Wilate, Nuwiq
Pfizer	888-240-9040	\$12,000	Xyntha, BeneFIX

Temporarily Uninsured and Need Factor and/or Hep C Medication?

Manufacturers also have programs to help you get your factor product free of charge on a limited basis if you are under or un-insured. Please speak with your HTC social worker. A list of factor assistance including the information from above is on the Hemophilia Federation of America website at: www.hemophiliafed.org.

Insurance Premium Assistance

The agencies below provide premium assistance on a case-by-case basis. Generally, if you're having difficulty paying for premiums and you utilize a large amount of factor (usually a severe hemophilia patient). *Please talk with your HTC or Cascade Social Worker.*

Michigan: Children's Special Health Care Services (CSHCS)

Ohio: BCMh or Medicare Premium Assistance Program (MPAP)

Indiana: Indiana State Hemophilia Insurance Program (ISHIP)

National: PSI Premium Assistance Program

Provides peace of mind to patients living with specific chronic illnesses by providing financial assistance to eligible persons by:

- Subsidizing the cost of health insurance premiums
- Providing pharmacy and treatment copayment assistance
- Assisting with Medicare Part D co-insurance
- Providing travel assistance for transportation reimbursement

Call 800-366-7741 or apply at www.patientservicesinc.org

HIV Prescription Assistance Programs (HIV Medications only)

Michigan Drug Assistance Program (MIDAP)
Call 888-826-6565

Ohio Drug Assistance Program (OHDAP)
Call 800-777-4775

Indiana AIDS Drug Assistance Plan (ADAP)
Call 866-588-4948

Medicare Guidance

The agencies below provide high quality and accessible health benefit information and counseling, supported by a statewide network of unpaid and paid skilled professionals. These individuals are NOT in insurance sales and provide unbiased information and can help older adults and the disabled choose a Medicare or Medicaid plan.

Also, your HTC or Cascade social worker will not choose a plan for you, however, can guide you on what to look for when choosing a Medicare plan. It's a great place to start!

Michigan Medicaid Medicare Assistance Program (MMAP)

Call 800-803-7174 or visit www.mmapinc.org

Indiana State Health Insurance Assistance Program (SHIP)

Call 800-452-4800 or visit www.Indianaship.com

Ohio Senior Health Insurance Information Program (OSHIIP)

Call 800-686-1578 or visit <http://www.insurance.ohio.gov>

Legal Resources

PSI ACCESS Program

A National Legal support hotline answers questions regarding: insurance issues, work accommodations, school accommodations, Family Medical Leave Act and more.

Call the ACCESS hotline at 877-851-9065

Michigan Protection and Advocacy Services (MPAS)

Michigan Protection & Advocacy Service, Inc. (MPAS) is the independent, private, nonprofit organization designated to advocate and protect the legal rights of people with disabilities in Michigan. MPAS services include information and referral, resolution of disability-issues, short-term assistance, and selected individual and legal representation.

Call 800-288-5923 or visit www.mpas.org



Educational Resources

Education resources including brochures and articles related to your life with a bleeding disorder are available. Topics include, but are not limited to: Bleeding Disorder Education, vWD specific information, Choosing Appropriate Childcare, Treating Siblings Fairly, Speaking to Your School, Longer Lasting Products, and more!

✓ Cascade Hemophilia Consortium: 734-996-3300

✓ Your local Hemophilia Treatment Center

✓ National Hemophilia Foundation – HANDI
1-800-42 HANDI (4-2634)
Some topics can be accessed on-line at, hemophilia.org.

✓ Pharmaceutical Companies/Manufacturer of your bleeding disorder product.

✓ Your local Hemophilia Foundation



Career Resources

Michigan

Michigan Rehabilitation Services

Works in partnership with individuals with disabilities to prepare for and obtain competitive employment, including exploring the possibilities of self-employment or owning a small business. Employment services to individuals with disabilities are provided in all 83 Michigan counties. Visit www.michigan.gov/mdhhs

Ohio

Bureau of Vocational Rehabilitation (BVR) Ohio

Placement in an employment setting suitable to your skills and capacities is the ultimate goal. Following training, we can provide placement assistance to you including resume development and practice interviews to get you ready for the job search.

Vocational training might include vocational school, college, technical or business school, or on-the-job or supported employment training. If supplies such as textbooks or tools are required for vocational training, or licenses and equipment are necessary to begin an occupation, OOD can help with those items.

888-282-4536 or ood.ohio.gov/Core-Services/BVR/Purpose

Indiana

Indiana Hemophilia and Thrombosis Center

Career counselors play a critical role in helping patients with bleeding and clotting disorders accomplish goals, and have success throughout the lifespan. For further information or to schedule an appointment, please call the main office number, 317-871-0000, or toll-free number, 877-CLOTTER (877-256-8837).

Indiana Vocational Rehabilitation Services (VR) Provides quality individualized services to enhance and support people with disabilities to prepare for, obtain or retain employment. The individual will work closely with a VR counselor throughout the process. Please visit: secure.in.gov/fssa/ddrs/2636.htm or call 800-457-8283 to locate your nearest office.

