

YOUR CHILD'S SCHOOL AND YOU: *Partnerships for Disabilities Assistance*

By Janet Brewer, M. Ed.

If your child is diagnosed with any of the disabilities listed, and they require specialized instruction, they could qualify for an Individualized Education Plan (IEP).

There are two federally mandated plans that can entitle school-age students for assistance. States also are mandated to provide special education services or related services and accommodations to children with a diagnosed disability.

The Individuals with Disabilities Education Act (IDEA) of 1974 [Amended 2004] requires states to provide a “free appropriate public education” to children with disabilities so they can be educated to the fullest extent possible with other children. If qualified, children are provided with special education AND related services under an IEP. Specialized instruction is defined as adapted instruction designed to meet the unique need of the child with a disability. This means the content, methodology, or delivery of instruction is changed to ensure the child’s access to the general curriculum. A bleeding disorder fits into the IDEA’s “Other Health Impairment” category, which is defined as impairment due to chronic or acute health problems such as asthma, attention deficit disorder, or hemophilia that adversely affect a child’s educational performance.

The Section 504 of the Rehabilitation Act of 1973 focuses on nondiscrimination. It maintains that “no otherwise qualified individual with a disability will be excluded from participation in, be denied the bene-



Bleeding disorder community teens on a Teen Connection trip

fits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.” The Americans with Disabilities Act (ADA) of 1990 serves as an extension of Section 504, providing for the elimination of barriers related to accessibility for the disabled to buildings, transportation, and communication. Both Section 504 and ADA also provide related services and accommodations to qualified individuals with a disability through a 504 plan. The intent is to provide access or remove barriers to participation. It provides students with the same rights and services as their “non-disabled peers.”

Continued on page 5



Qualifying Disabilities for IDEA and IEP Assistance

- Physical, sensory, mental, or emotional
- Emotional disturbance
- Orthopedic impairment
- Hearing-vision impairment
- Autism
- Traumatic brain injury
- Other health impairment
- Specific learning disability
- Multiple disabilities

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EXECUTIVE CORNER



Dear Members of the Bleeding Disorders Community,

If you were one of the 173 million people in the United States affected by the August heat wave, you will understand the significance of weekend getaways, afternoons in the pool, or a nice walk (bike ride) in the

shade. For each of us, summer is a time for individuals and families throughout the bleeding disorders community to enjoy community gatherings, family camps, and quality time with friends and family. We hope you had an enjoyable summer filled with good health and great connections, plenty of water, and air conditioning!

With fall approaching, many parents and students are sure to be preparing to return to school. For some of us, this involves time planning a child's Health Plan, IEP, or 504. For those of us working for an employer that provides a health benefit, fall is routinely the time to sign up for next year's health benefits during open enrollment. Each of us affected by a bleeding disorder has a lot to learn and know in order to make good choices for the coming year. We hope this issue of *Dateline Federation* offers support and tips to help with your planning.

The national debt and annual deficit spending by Congress will continue to create significant volatility in our ability to access care. With uncertainty over funding for entitlements (i.e., Medicare, Medicaid, and Social Security) the potential impact of cuts to programs that directly serve our bleeding disorders community is a critical issue during the year ahead, as well as in the foreseeable future.

We encourage you to stay connected as advocates and be ready to work with your local organizations and national organizations like HFA to champion the needs of our community when issues arise. We have a choice to be involved and speak up; let's take advantage of it every chance we get!

Thank you for your active role in the bleeding disorders community. Enjoy!

Sincerely,

Paul Brayshaw
Board President

Kimberly Haugstad
Executive Director

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The Hemophilia Federation of America is a national non-profit organization that assists and advocates for the bleeding disorders community.

Dateline Federation is published four times a year by the HFA, 210 7th St., Ste. 200B, Washington, DC 20003. Toll Free Number: 800.230.9797; Local Number: 202.675.6984; Fax: 202.675.6983. Requests for permission to translate and/or reprint contents of *Dateline Federation* should be directed to the Editor at info@hemophiliafed.org. *Dateline Federation* is available as a PDF file from the HFA website at www.hemophiliafed.org.

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The material provided in *Dateline Federation* is provided for general purposes only. HFA does not give medical advice or engage in the practice of medicine and recommends that you consult with your physician or local treatment center before beginning any form of treatment.

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Calling All Dads

By Jane Cavanaugh Smith

How does life change when you become a father? The better question might be how does it not change? Schedules, priorities, relationships with other family members, work/life balance—from the most mundane to the most profound—almost everything in your life is impacted by the arrival of that little person. Along with that come the immense love and joy, a boatload of new responsibilities, and a certain amount of personal reflection. All of that said, what kind of dad do you want to be?

The importance of a child having a present and engaged father cannot be underestimated. Research has continuously shown that children with involved fathers on average:

- Do better in school
- Have a greater motivation to succeed
- Gain higher self-esteem and greater confidence in unfamiliar settings
- Are less likely to be delinquent or abuse substances like drugs and alcohol

This research, combined with the understanding that one of the greatest strengths of the bleeding disorder community is our ability and desire to educate and support each other, led to the creation of *Dads in Action*. Launched in 2003 by community members Joey Privat and Tom Vaclavik, HFA's Dads in Action program remains committed to creating a network of men in the bleeding disorders community who **educate, support, and challenge each other** as they strive to be proactive and responsible role models for their children and families. Through monthly webinars, on-line resources, and national and local events, *Dads in*

Action addresses general fathering topics, such as communication and discipline, as well as issues and concerns specific to having a child with a bleeding disorder, or being a dad who has a bleeding disorder.

Though most kids grow up knowing dad is a pretty busy guy, they also need to know in that busy life they are the priority. Please join us as we strive to strengthen families and our community, one dad at a time. Visit www.hemophiliafed.org/what-we-do/programs-and-services/dads-in-action/ for more info on *Dads in Action!*

Dads in Action is led by Program Coordinator Jane Cavanaugh Smith, parent of an 18-year-old with severe hemophilia, who has worked extensively on bleeding disorder programming both in the New England community and at the national level. Jane welcomes your feedback or questions and can be reached at j.smith@hemophiliafed.org ■■



Jane Smith and family: Chris, Leland and Taylor

“Through monthly webinars, online resources, and national and local events, Dads in Action addresses general fathering topics, such as communication and discipline, as well as issues and concerns specific to having a child with a bleeding disorder, or being a dad who has a bleeding disorder.”



**CHECK OUT THIS
ONLINE
RESOURCE!**

www.wrightslaw.com

The Wrights Law website is a great tool for families, educators, and advocates to learn more about special education law and school advocacy for kids



Blood Sisterhood Online Community

Linda E. Wyman-Collins (Lew) BSN, RNC-NIC

Have you considered becoming part of the Blood Sisterhood? Would you like to connect with other women around the country and share in a more secure venue than on other networking sites? The opportunity is now online to share and gain the help and support you may need. I invite you to join HFA's Online Community.

Also, becoming a member of the Blood Sisterhood is an excellent opportunity to connect with other women experiencing the same challenges and experiences in life. I know I often need the support and knowledge of other women, but don't want everything about me to be common knowledge to everyone online. As medical professionals, we are discouraged from posting personal and medical issues online. It is common

practice for employers now to research you on social networking sites when you apply for a job, and patients and families research you online.

The Online Community allows for sharing on a social level or joining specific groups, such as Blood Sisterhood or Partners. Once you have registered, you just wait to be approved. You can make posts in different categories, join other posted topics and discussion forums, or learn from what is already posted. You can also help one another with shared knowledge to help make decisions and gain coping skills. You also have the opportunity to share photos. And just like on Facebook, you can limit your contacts as desired.

In the past, HFA held a webinar on how to navigate the site. It can be repeated if the need is out there. Please feel free to join and give us your feedback.

Register today at <http://community.hemophiliafed.org/>

STAY CONNECTED!

When people with rare medical concerns remain silent, their needs will be overlooked.

Please get involved today!

- **Connect on Facebook:**
www.facebook.com/hemophiliafed
- **Sign Up for Legislative Alerts:**
<http://hemophiliafed.org/advocacy/legislative-action-center/>
- **Join the Online Community:**
<http://community.hemophiliafed.org/>



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GET INFORMATION ABOUT *Living fit with hemophilia:*

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- 2 Train** with the Living Fit! Fitness Guidelines and meet the Physical Therapist Fitness Team who developed them especially for young people with hemophilia
- 3 Download** the first FREE mobile app to help you keep your factor on track

START LIVING FIT TODAY! LEARN MORE AT www.LivingWithHemophilia.com/LivingFit

 **CARDIO**

 **STRENGTH**

 **NUTRITION**

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Update: Hemophilia Association of New Jersey (HANJ)

HFA greeted a new Blood Brotherhood site this summer with the addition of The Hemophilia Association of New Jersey (HANJ). This marks the 12th HFA Member Organization to join the Blood Brotherhood program. HANJ will provide local face-to-face meetings for adult men with bleeding disorders. Tom Russomano and Rich Vogel will serve as the site coordinators for HANJ's Blood Brotherhood site.

The New Jersey Blood Brothers kicked off their first event on July 24th with dinner and a presentation on weight management. Tom and Rich are now busy planning future Blood Brotherhood events. HFA heartily welcomes the New Jersey Blood Brothers!

Update: Bleeding Disorders Association of the Southern Tier (BDAST)

HFA is proud to introduce Marty Tully as the new Blood Brotherhood site coordinator for the Bleeding Disorders Association of the Southern Tier (BDAST). Marty joins his fellow BDAST coordinators in planning future events for the Blood Brothers in up-state New York.



Martin Tully and Chad Blair

On June 4-5, the Blood Brothers of BDAST traveled to New York City to meet other Blood Brothers in the area. They first gathered for an evening of learning about post traumatic stress in the bleeding disorders community. The following day, the Blood Brothers worked up a sweat together as a team in the New York City Hemophilia Chapter's walk.

To find out how you can get involved with Blood Brotherhood, contact HFA at 1-800-230-9797 or hfaprograms@hemophiliafed.org ■■



Joe and Sam Z.

Continued from page 1

The ADA/504 provisions define a Medically Related Disability as a physical or mental impairment which substantially limits one or more major life activities or those basic activities that the average person in the general population can perform with little or no difficulty. Major life activities as they relate to bleeding disorders may be defined as walking, writing, sitting or standing. Related services may include:

- Speech/language therapy
- Audiology (hearing loss)
- Psychological
- Physical/Occupational therapies
- Counseling
- Rehabilitative counseling
- School health services
- Transportation

So if you are comfortable with your school district's physical therapist, for instance, the physical therapy (PT) could be included on your child's ADA/504 plan, and they could receive PT during the school day. (Parents should plan on providing the therapist with additional information on physical therapy for the individual with hemophilia, as well as contact information from the ordering physician to ensure the therapist proceeds slowly.)

Reasonable accommodations can also be provided under these provisions to remove barriers to access. These accommodations might include:

- Walkie-talkies for nurse and recess/duty aids
- Extended travel time around building
- Permanent passes to the school nurse
- Permanent passes for school elevator

- Medications, needles, and supplies maintained and locked in the nurse's office
- Scheduling of physical education activities several days in advance
- Field trips to include nurse or parent
- Extra sets of books at home
- Extended time for homework/make-up work
- Regular email contact from teachers
- Medically-related absences may be excused with no loss of credit
- Lecture notes or presentations available electronically
- Tutoring due to absence
- Staff in-service. ■■

Sources: Federal Regulations, Part 300

HOW DOES MY CHILD QUALIFY?	
●	If there are no academic, behavior or emotional concerns:
☑	Make an appointment with your building principal/ADA coordinator, teacher(s), and school nurse and ask to develop a 504/ADA plan.
●	If there are academic, behavior or emotional concerns:
☑	Write a letter to your child's teacher asking for a formal evaluation process
●	When assessments are complete:
●	1. A meeting will be scheduled
	2. Reports will be shared with you regarding your child's abilities
	3. The Student Assist Team will then decide if your child:
	✓ Has a qualifying disability
	✓ Requires specialized instruction in order to make progress.
●	Remember these as a personal guide:
	Disability + Specialized Instruction = Individualized Education Plan
●	Disability + Related Services/ Accommodations = ADA/504

Health Reform Alert: IPAB Reductions Looming

By Eboni Morris, HFA Policy Manager

What is the Independent Payment Advisory Board (IPAB)?

The Patient Protection and Affordable Care Act (PPACA) established a new Independent Payment Advisory Board (IPAB) within the Medicare program. It will have the authority to issue recommendations to reduce the growth in Medicare spending that exceeds a defined target growth rate.

IPAB will be an independent board housed in the executive branch and composed of 15 full-time members appointed by the President and confirmed by the Senate. Board members will be appointed to 6-year terms and serve no more than 2 terms. Most of the board members cannot be health-care providers and will be full-time federal employees. There will also be three ex officio (non-voting) members, including the Secretary of the Department of Health and Human Services, Center for Medi-

“...focusing on the end result of the healthcare system—the use of spending cuts—does not get at the true reasons behind rising costs in the Medicare system...”

care and Medicaid Services Administrator, and the Health Resources and Services Administration Administrator. IPAB will also have a Consumer Advisory Council with 10 members—one from each HHS region. IPAB will be funded through the Medicare Trust Fund.

IPAB recommendations will be considered by Congress and implemented by the Administration on a fast-track basis. The recommendations made by IPAB move to the Congress, bypass certain Congressional procedures, and default to the Secretary for implementation if Congress does not act. There is no administrative or judicial review process should Congress not implement IPAB's recommendations. IPAB must provide a rationale for its proposals and be certified by the Centers for Medicare and Medicaid Services (CMS) Actuary to ensure that they will actually save money based on the targeted growth rate. It is important to note that sometimes the CMS Actuary's projections on Medicaid spending differ from the Congressional Budget Office (CBO), which advises Congress, and/or the Office of Management and Budget (OMB), which is responsible for the President's budget. This has in many instances put Congress, CMS, and the White House at odds over Medicare spending. Medicare is projected to increase from 3.6% of GDP to 5.9% in 2035 (assuming provider cuts). If no provider cuts are passed by Congress, Medicare is projected to rise to 7% of GDP by 2035.

The Role and Authority of the IPAB Remains Unclear

With all of the details still being interpreted, opinions on IPAB span a range of ideo-

IPAB TASKED BY PPACA TO REDUCE PROJECTED MEDICARE SPENDING

Between 2015 and 2019, IPAB can look at the following areas to target spending reductions: Medicare Advantage, Medicare Part D, skilled nursing facilities, home health care, dialysis payments, ambulance and ambulatory surgical centers, durable medical equipment (DME) payments, and (in 2016) payments to clinical labs. However, IPAB cannot change premiums, change benefits, change eligibility and taxes, or initiate other changes that would result in “rationing” of health care. At 2020 and beyond, it is possible hospitals, inpatient rehabilitation centers, psychiatric facilities, long-term care hospitals and hospices can be included as spending reduction targets.

logical arguments. The President's National Commission on Fiscal Responsibility and Reform and the President himself have advocated for strengthening the role of IPAB to help curb spending. In its current form, they feel IPAB does not have the mechanism to immediately drive sharp changes in spending within the program. IPAB backers argue that its creation came out of Congressional inefficiency and its inability to make decisions to slow Medicare growth in a timely fashion. However, others—including many in Congress, patient/consumer groups and additional health industry stakeholders—feel that IPAB is a gross over reach of executive government power and will lead to the rationing of healthcare to Medicare beneficiaries. They also believe that focusing on the end result of the healthcare system—the use of spending cuts—does not get at the true reasons behind rising costs in the Medicare system.

Currently, there are two bills aimed at repealing IPAB in Congress that have bipartisan support and support from some patient and consumer groups: the Medicare Decisions Accountability Act (H.R. 452) introduced

HFA SUMMER POLICY ACTIVITIES

- Jonathan Vanderburg joins HFA as a policy/advocacy consultant focused on state activities.
- **June 27–30**, Biotechnology Industrial Organization (BIO) International Convention, Washington, D.C.
- **August 8–11**, National Conference of State Legislatures (NCSL) Annual Legislative Summit, San Antonio, Texas.
- Monitor health policy issues impacting the bleeding disorders community.
- Visit the Advocacy section of the HFA website for more information on important issues we are currently following.

by Representative Poe (R-TN) in the House and the Health Care Bureaucrats Elimination Act (S. 668) introduced by Senator Cornyn (R-TX) in the Senate.

At this time, HFA has not committed to supporting either of these bills—or any other call for the repeal of IPAB—and we will continue to be engaged in the issue. In July HFA worked with the American Plasma Users Coalition (APLUS) to send a letter to Congress to voice concerns about certain parts of IPAB's structure. ■■

**Interested in more details about IPAB?
Check out the information
at these sites:**

- IPAB action center : <http://ipabactioncenter.org>
- Kaiser Family Foundation: www.kff.org or www.kaiserhealthnews.org
- Politico: www.politico.com
- The Hill: www.thehill.com

HFA/(APLUS) Recommendations to Congress:

- IPAB's recommendation processes should allow for meaningful stakeholder engagement
- IPAB's policies should not adversely impact easy access of patients to specialists
- IPAB's cost-containment strategies include an evaluation of patient-oriented outcomes
- IPAB's authority be clarified in order to provide beneficiaries a better understanding of what IPAB can and cannot recommend with respect to Medicare benefits
- There should be an established review or appeals process when IPAB recommendations will negatively impact access to quality patient care

Additional Resources on Healthcare Reform Implementation

- State Reform <http://www.staterforum.org>
- Kaiser Health Reform State Map <http://healthreform.kff.org/the-states.aspx>

Important Healthcare Reform Deadlines

(October 2011) Medicaid Long-Term Care Services creates the State Balancing Incentive Program in Medicaid and establishes the Community First Choice Option in Medicaid to provide community-based attendant support services to certain people with disabilities.

(January 2012) Annual Fees on the Pharmaceutical Industry imposes new annual fees on the pharmaceutical manufacturing sector.

(January 2012) Accountable Care Organizations in Medicare allows providers organized as accountable care organizations (ACOs) who voluntarily meet quality thresholds to share in the cost savings they achieve for the Medicare program.

(January 2012) Medicare Advantage Plan Payments reduces rebates paid to Medicare Advantage plans and provides bonus payments to high quality plans.

(January 2012) Medicare Independence at Home Demonstration creates the Independence at Home demonstration program to provide high-need Medicare beneficiaries with primary care services in their home.

(Fiscal Year 2012) Medicare Provider Payment Changes adds a productivity adjustment to the market basket update for certain providers, resulting in lower rates than otherwise would have been paid

(January 2014) Health Insurance Exchanges to view which states have received planning grants go to www.statehealthfacts.org.



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and we're exploring ways to make factor last longer. Backed by 30 years of biotechnology leadership, our goal is to make progress for the hemophilia community. As we blaze a new trail of scientific discovery toward long-lasting factor, we're also creating programs and resources with the potential to change lives.

Join us as we move hemophilia treatment forward.

➤ Sign up for updates on our progress.
www.BiogenIdecHemophilia.com



FitFactor – Supporter Lamb is a Lion of Exercise

Having hemophilia doesn't mean you or your child must live a sedentary life or be cut off from good opportunities for becoming fit. Just ask Terry Lamb of Virginia. This 59-year-old supporter of the FitFactor program lifts weights 6 days a week and swims on his day off.

Back when Terry was born, there was no such thing as prophylactic treatment. The doctors told his parents he would only live to be 8 years old. Upon hearing the news, his father declared, "I don't care how long we have him. He will be a full-fledged boy." Terry had bleeds, of course, but says he grew up "very normal" despite his hemophilia.

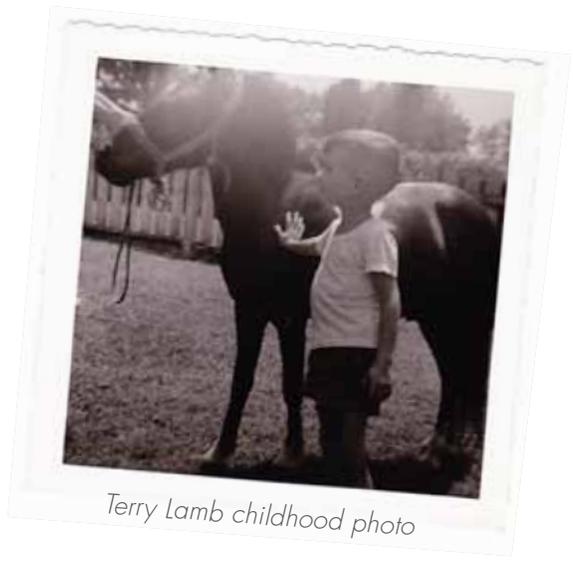
Terry wishes he could have had the opportunities he has now when he was younger. "Unfortunately... I hadn't started [exercising] young. I'd be in a lot better shape than I am now," he says. Terry encourages young people with hemophilia "to utilize what they have today... There is so much freedom. I never thought I would have the freedom this late in life that I do today."

"I encourage the young people to exercise; get out and participate in the sports that are safe for them to do," Terry says. A horse trainer by profession, he continues to ride and train as a hobby. "I can go out, ride my horses safely, and not worry about anything."

Terry believes anyone with drive and determination can stay on top of their health, no matter what hurdles they may face. "I'm not going to sit here and tell you it's easy," he says. "It's not." But he stresses that anybody can do it. "Just stay on top of things, research, study, exercise, eat right, take your vitamins, get your rest, and you'll be all right... you can reach any goal you want to..." Terry should know. He has outlived his doctor's prediction by 51 years, and he has gone 9 years without a bleed. He can partly thank his infusions for that, but he knows taking care of his hemophilia is just one part of a healthy lifestyle. He hopes his story will help young people realize the same.

Terry is a prominent voice in HFA's FitFactor program, which encourages patients with hemophilia to focus on living a fit and healthy life. To learn more about the FitFactor, visit <http://fitfactor.hemophiliafed.org/>.

Learn more! It's free! Sign up at
<http://fitfactor.hemophiliafed.org>



Terry Lamb childhood photo



Current photo of Terry Lamb with Faith Hunter



Terry Lamb childhood photo

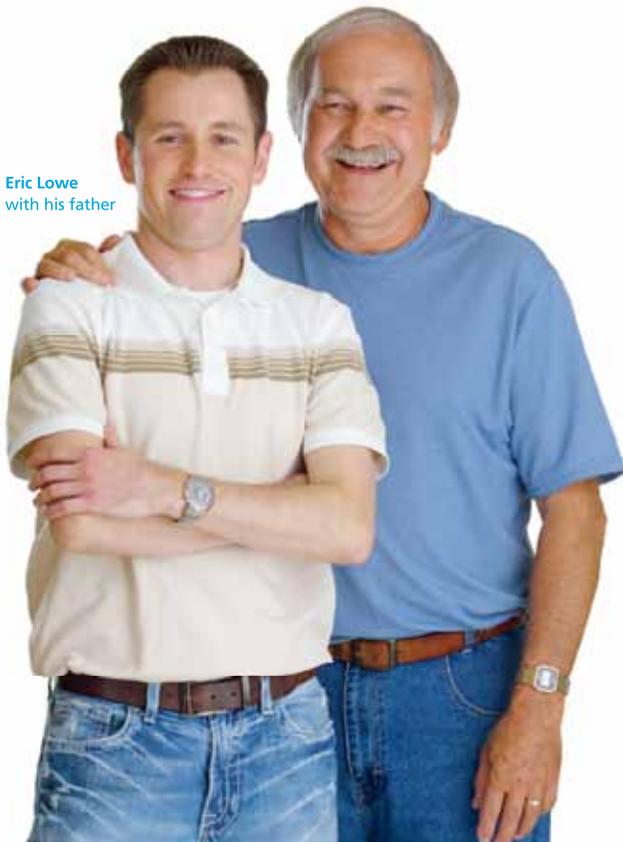
"Just stay on top of things, research, study, exercise, eat right, take your vitamins, get your rest, and you'll be all right...you can reach any goal you want to..."



SAFE		MODERATE		DANGEROUS	
aquatics	golf	aerobics	rowing/crew	BMX racing	trampoline
archery	hiking	bowling	running/jogging	boxing	weight lifting
elliptical machine	snorkeling	cardio kickboxing	skiing (cross-country)	diving (competitive)	(power lifting)
fishing	stationary bike	dance	stepper	football	wrestling
Frisbee® disc	swimming	diving (recreational)	T-ball	hockey	scuba diving
tossing	tai chi	jumping rope	tennis	(field, ice, street)	skateboarding
	walking	rock climbing	ultimate Frisbee®	lacrosse	skiing (downhill)
		(indoor)	yoga	motorcycling/ motor cross racing	skiing (telemark)
		roller-skating		power lifting	snowboarding
SAFE-MODERATE		MODERATE-DANGEROUS		rock climbing	soccer
				(natural setting)	softball
biking	rowing machine	baseball	karate	rodeo	surfing
body sculpting	ski machine	basketball	kayaking	rugby	track and field
circuit training	spinning	canoeing	kung fu	scooter (motorized)	volleyball
Frisbee® disc golf	treadmill	cheerleading	mountain biking	snowmobiling	waterskiing
Pilates	weight lifting	gymnastics	racquetball		
physioball	(resistance training)	horseback riding	river rafting		
		ice-skating	scooter		
		inline skating	(nonmotorized)		
		Jet Ski®			

Chart adapted from *Playing it Safe. Bleeding Disorders, Sports and Exercise*, courtesy of the National Hemophilia Foundation.

Eric Lowe
with his father



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New Strategies to Fund a Unique and Needed Program at HFA

For over a decade, HFA has been actively supporting emergency financial needs of individuals and families with bleeding disorders through the Helping Hands Program. This program aids hundreds of people with bleeding disorders each year and assists with basic living expenses, such as mortgage payments, food, and electric bills to help an individual or family through a crisis.

Unfortunately, the Helping Hands Program is now underfunded and in jeopardy of closing for the year. HFA continually looks for new resources to sustain the program. HFA is experimenting with a dedicated fundraiser in 2011, the Gears for Good bike ride. With everyone's support, we can keep Helping Hands open through year end with this fundraiser. In 2010, we made an organizational decision to direct individual membership funds to the program and **thank each of you** who have become an annual member of HFA. Your contributions will go directly towards helping families.

We encourage people with bleeding disorders to live healthy, active lifestyles—we know people with strong and active bodies have less painful bleeding episodes. The Gears for Good bike ride and fund raising event blends our belief in health and wellness with a commitment to support Helping Hands, which is a critical program that desperately needs additional funding and support.

The **Gears for Good** fundraiser co-chairs, Barry Haarde and Paul Brayshaw, can attest to the health benefits of bicycling. Barry said in a recent interview, "I believe that the conditioning afforded by cycling is at least partially responsible for my relative good health in spite of liver cirrhosis from hepC." Barry explained that studies have shown hepC progresses much faster in those who are overweight and out of shape, and the liver benefits as much from aerobic exercise as does the heart. Paul commented recently, "Bicycling has been integral to maintaining my fitness, as well as giving me an opportunity to see the world!" Paul is a long-time bicyclist and Barry has logged thousands

"Because of your organization and support, my son and I are able to stay in our home, and that means the world to us. Being unemployed and my son's medical issues can be challenging, but with the heart of others, we are making it day by day."

HOW YOU CAN HELP GEARS FOR GOOD



Ride donations will remain open for 30 days after the Bike Ride.

Please consider supporting the event or joining HFA as a member today and contributing to this important program at

<http://hemophiliafed.org/get-involved/fundraisers/2011-bike-ride/>



of miles on his bicycles. "I began using a hybrid bike and began doing 10–20 mile rides on the neighborhood bike trails and then started showing up at local bike club meets; then I bought my first road bike," Barry remarked. "I reached higher mileage goals of 50, 110k, and then 100 mile rides. I reached a personal best this year of a 150 mile ride in one day. I've also ridden three consecutive hundred mile rides this year and hit a new one week record of 400 miles in one week."

About the Bike Ride Chairs

Ride Co-Chair: Barry Haarde

I originally took up cycling in the late nineties to strengthen my muscles around the knee prior to knee replacement surgery.

I've ridden over 50,000 miles since taking up the sport and have participated in nine MS150s and many other local charity fundraising rides—but I have never had the opportunity to ride for hemophilia until the Gears for Good ride.

My ultimate goal is to ride across the U.S. next year. I also ride to raise awareness for HIV and hepatitis C.

Helping Hands[™]
Hemophilia Federation of America

GEARS FOR GOOD BIKE RIDE AND FUNDRAISER

September 15 – 17, 2011
3 Days | 156 miles
West Virginia to
Washington, D.C.

Ride Co-Chair: Paul Brayshaw

In 1973, I was born in Denver, Colorado with severe hemophilia B. I am the only person in my family to have hemophilia, but I am not the only one affected.

With an older brother, two sisters, supporting parents, a loving wife, and most recently a baby boy, we have all confronted the challenges of my bleeding disorder and endured the frustration.

But moreover, we continue to discover the daily glimmers of hope and happiness related to this illness. ■■



Paul Brayshaw riding.



Left: Barry Haarde riding.

Right: Paul Brayshaw with his family.

Bottom left: Andy Matthews getting ready to ride.

Bottom right: Andy's son Keeton in training.



Understanding Your Choices (Part 1)

This is the first in a series of articles about health insurance choices. I don't know about you, but every time I have to choose an insurance plan, I feel totally daunted. I know that the wrong decision has the potential to cause my family serious financial damage and a lot of heartache and headache dealing with claims and physician choices. So it is critical that I have the right information and tools for making a good choice, since the people who would ultimately suffer from a bad choice are me and my family.

This first article will provide you with a basic understanding of some of the types of health insurance out there so that you can start considering what type of plan would work best for you. I will focus on private insurance and TRICARE (insurance provided to military personnel, retirees, and their dependents), but I plan

to provide information on Medicaid and Medicare in a future article, so stay tuned.

I'm not an insurance professional. I am a consumer who (possibly, like you) has had some really frustrating moments with insurance companies and medical providers. Getting more information out there will hopefully help people in the bleeding disorders community to make more informed decisions and prevent potential frustrations. (How many of us have received a bill for \$15,000, or maybe even \$100,000, and were faced with fighting the insurance company for coverage? A future article will cover strategies for winning that particular battle.)

The first step in making an informed decision is learning some of the lingo. Here are the types of health insurance you may be choosing from for coverage:

HMO: A *health maintenance organization (HMO)* is a managed care organization (MCO). This means that a network of medical care professionals and facilities has individual contracts with the insurance company to provide care at a certain (lower) cost. **The upside?** You don't usually have to worry about calculating percentages, deductible, and out-of-pocket costs. Almost everything is handled with co-pays. And claims are generally filed by the doctor's office, saving you paperwork. **The downside?** You must see a provider in the network and, on many plans, you need a referral from your primary care physician (PCP) to see any specialist or you won't be covered.

PPO: A *preferred provider organization (PPO)* is also an MCO. In order to get the cheaper rates for care, you must go to someone in your network. **The upside?** Again, most care is handled with co-pays,

someone out of your network, it will still probably cost more regardless of the referral.

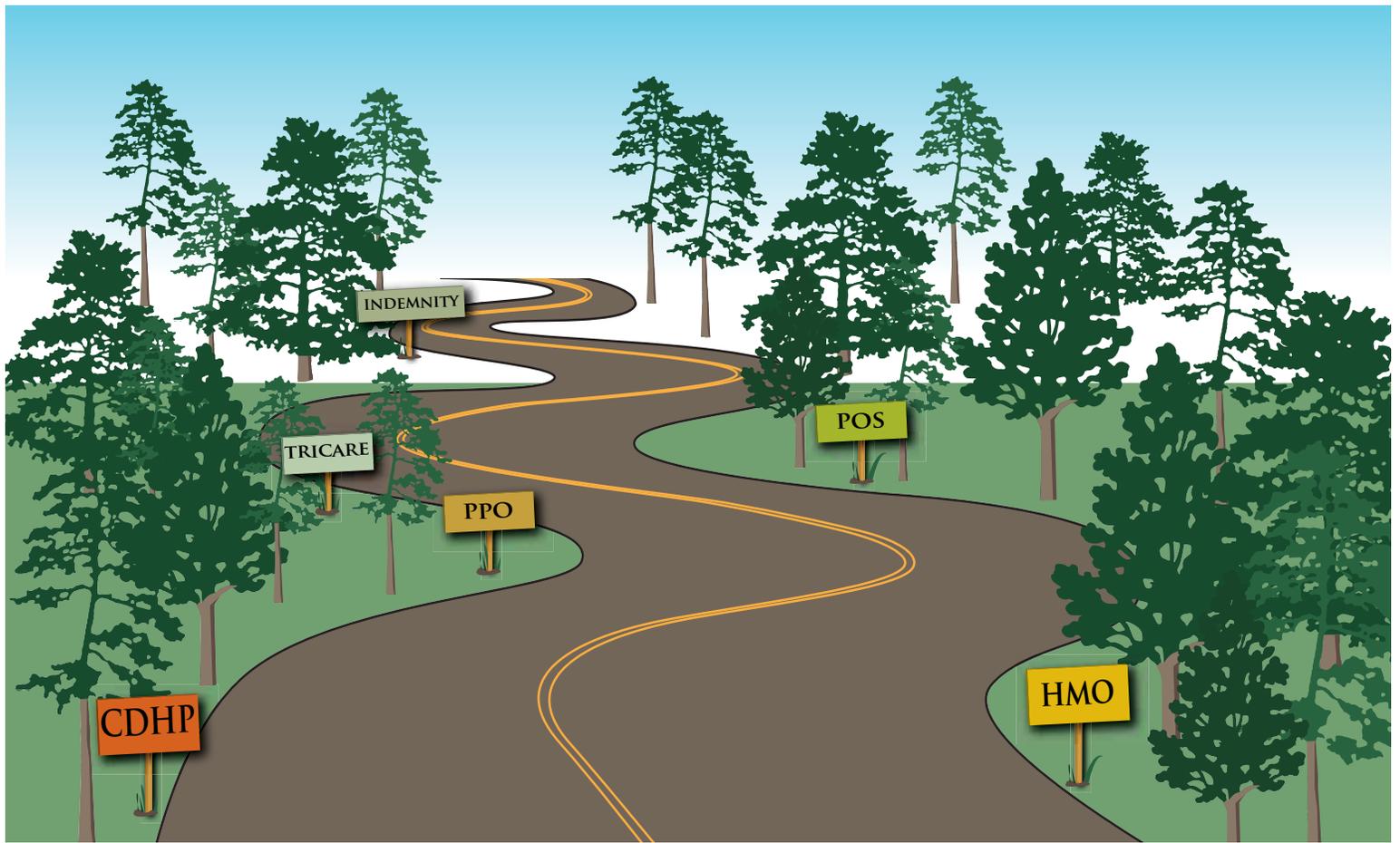
The upside? Again, most care is handled with co-pays, and you are still eligible for partial reimbursement if you go outside your network for care. **The downside?** You must have a referral from your PCP to go to a specialist. Going outside the network for care will be more expensive, and you may still have to calculate deductibles, out-of-pocket expenses, and other amounts and percentages. If you are referred outside your network, you will probably have to do your own claims paperwork as well.

CDHP: A *consumer driven healthcare plan (CDHP)* allows members to use personal Health Savings Accounts (HSAs) or Health Reimbursement Arrangements (HRAs) to pay routine medical expenses, while a high-deductible health insurance policy protects them from catastrophic medical expenses. If you use up your HSA, you start paying your "bridge," which is essentially your deductible. Once you have fulfilled paying your bridge, the insurance company starts paying its percentage again. If you have any funds left in your HSA, they roll over to the next year. **The upside?** CDHPs often have much lower premiums than other insurances. There may or may not be a network available to reduce your out-of-pocket expenses. Most preventive medical care is paid for until you reach your bridge, and some plans will continue to pay for preventive care even if you've reached your bridge. Any funds you have left at the end of the year go to the next year (though in our community, this could motivate a patient to avoid care to save that HSA, and avoiding care with a bleeding disorder is usually a bad idea). **The downside?** Folks in our community are going to hit that bridge and use up an HSA pretty fast, so there's not much chance of rolling HSA funds to the next year. Coverage tends to be a lot less comprehensive with more out-of-pocket costs in general. You pay for all of your own care while you are fulfilling the amount in your bridge.

"Getting more information out there will hopefully help people in the bleeding disorders community to make more informed decisions and prevent potential frustrations."

and you are still eligible for partial reimbursement if you go outside your network for care. You might not have to have a referral from your PCP to go to a specialist. Most claims are filed by the doctor's office, saving you paperwork. **The downside?** Going outside the network for care will be more expensive, and you may still have to calculate deductibles, out-of-pocket expenses, and other amounts and percentages.

POS: A *point of service (POS)* plan is another MCO. It combines the HMO and the PPO. You must select a PCP (from your network, of course) when you enroll. Your PCP is then your "point of service," and all further care goes through that doctor. Your PCP can refer you to any medical service in or out of your network, but if you see



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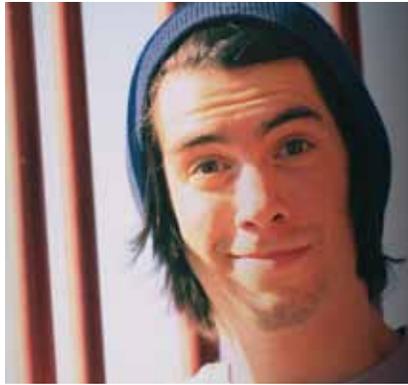
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.. HFA SCHOLARSHIP WINNERS ..

Ryan Shorosky

Ryan Shorosky is a landscape photographer whose work explores the importance of our connections to the natural world. He currently spends time in the province of Newfoundland where he portrays the environment and its inhabitants through large-format photography. He hopes to further investigate his own heritage in the area by tracing back his connection to hemophilia through photographs and visual media. Mr. Shorosky plans to publish a book of these photographs, along with his own writings.



Patricia DeRatto

Patricia DeRatto's youngest child, a boy, was born with severe hemophilia in May, 1991. This was completely new territory to her as neither of her other two children had any chronic medical problems. She was determined to learn all she could about hemophilia so that she could provide him with the medical care he needed. As he and her other children went through school, moving toward their goals, Ms. DeRatto realized that she was not being the best role model she could be. After considerable work, she has earned an Associate Degree and plans to enroll at John Tyler Community College to earn the credits needed to transfer to a 4-year university and earn a bachelor's degree in Sociology.



Tom Blake

Tom Blake just finished the spring semester of his sophomore year at Manchester College. Because math and numbers have always intrigued him, he aspires to a degree in accounting. After graduating from college and earning his CPA certificate, he plans to move to Chicago or Indianapolis. His goals are large, and he feels one of the main reasons he dreams big is because of being a member of the bleeding disorders community. Five years ago, Mr. Blake was invited to join a Youth Advisory Council, which inspired him to strive for greatness and taught him to dream big. The impact of this group on his personal development has been immense, and he will be forever indebted to the hemophilia community.

**“One person can
make a difference and
every person should try.”**

John F. Kennedy

Samantha Swygman

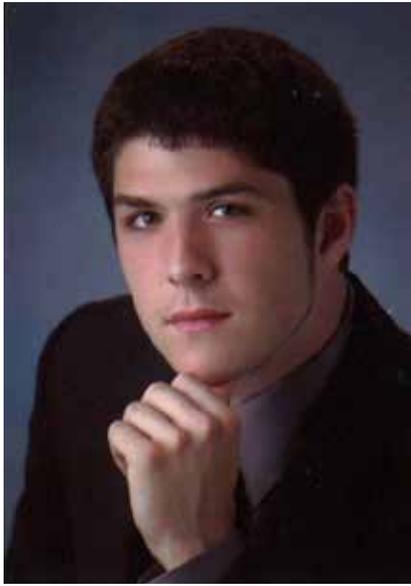
In order to prepare herself to wholeheartedly serve others, Samantha Swygman decided to serve for a year after high school as a missionary, assisting the community around her in countless ways. She plans on attending the University of Georgia in the fall, where she can devote herself to studying the art of nursing. Going forward, she is filled with enthusiasm for her future patients who, regardless of their state in life or physical ailment, will need love and encouragement.



Rex Climer III

Rex Climer III is finishing his freshman year as an engineering major with a minor in agriculture at the University of Tennessee at Martin. He wants to specialize in agricultural engineering to help in the design and maintenance of tractors and the computers that are now integrated into nearly all agricultural equipment. His love of the outdoors and enthusiasm for hands-on work can be a challenge for a person with a severe bleeding disorder, but he keeps himself in good physical shape in order to protect his joints and maintain excellent coordination.





Travis Albright

Travis Albright is currently applying for admission to, and hopes to graduate from, the Gerald Ford School of Public Policy by the end of his senior year at the University of Michigan. The hemophilia community has been a profound influence in both his current career choice and in his life. He has constantly been inspired by the children, young adults, and role models who have taught him so much. In the future, Mr. Albright plans to become more involved with advocacy for the hemophilia community by educating those who plan for careers in the field of public health policy.

Jordan Horn

Jordan Horn believes that one of the greatest things a person can do is help others. Her sister's struggle with different illnesses, including von Willebrands, throughout her life has influenced her desire to go into the medical field, where she can combine her love for science with her love for volunteering and helping people. Miss Horn believes that dreams are one of the most important things to hold on to; they give you something to strive for and believe in. Her dream is to attend Olivet Nazarene University and help others by becoming a physical therapist or a physician's assistant.



Eric Shepherd

Eric Shepherd currently attends Wright State University, and is working on an undergraduate degree in Biology, while taking pre-med courses for entry into medical school. His career goal is to become a doctor and specialize in infectious disease or hematology/oncology. His aspirations include continuing to serve in areas of the world that have great physical and emotional needs. Mr. Shepherd hopes to live a life that makes a difference to those around him.



Kristi Friesen

Choosing an academic field was not difficult for Kristi Friesen. Based on her love of healthy eating, she decided early on that she wanted to be a dietician and practice clinical dietetics. Over time, her desire has evolved to incorporate a focus on HIV and the practical application of nutrition as a form of treatment. Because she grew up in the hemophiliac community (her two brothers have severe factor nine deficiency and she is a carrier), Ms. Friesen has had an interest in HIV for a long time. She transferred to Bastyr University in the fall of 2010 to complete her bachelor's degree in Nutritional Sciences.



Ryan Lally

Ryan Lally will be attending the University of the Sciences in Philadelphia in their 6-year Doctor of Pharmacy program because he believes he would make an excellent pharmacist. Because he suffers from von Willebrands Disease, he knows how important a good pharmacist can be to an individual. He understands how important it is for a pharmacist to work with both the patient and doctor to find the proper treatment protocol, and knows exactly how the research, manufacturing, and distribution of medication can, indeed, make a difference in a person's life. Mr. Lally wants to be a part of this process.



.. YOUNG LEADERS ..

New Video Voices from Young Leaders

HFA's new Media Task Force is working hard to bring the bleeding disorders community insightful and informative videos directly from their local communities. This recently formed group of 13 members from the Young Leaders at Symposium, ranging in age from 18 to 30, participated in a hands-on experience to help get them started. David Ford, an accomplished film director, facilitated a three-day workshop to help provide these young leaders with the tools to collect a personal story through taped interviews. Each participant was provided a camera and taught techniques and skills for capturing quality video.

Joe Tavarez, a Young Leader from Texas, has created a video of an interview captured with a Spanish-speaking mother named Julie Mora. Though he was on a tight deadline to create this video before the Texas state meeting that was held in June, Joe completed the project on time and went well above and beyond all expectations. When Kimberly Haugstad, HFA Executive Director, shared the video with the Texas community, she commented, "The Texas community is proud of the video Joe did and we can't wait to see the other Young Leaders' work!"



Joe Tavarez, Young Leader from Texas

HFA is excited to have Joe as a committed member of the Media Task Force. He is a dedicated, hard worker and can help us connect with the Spanish-speaking community members! Check out Joe's video here: <http://voices.hemophiliafed.org/2011/07/julie-mora/>

Also be on the lookout for more Young Leaders videos! David Ford and our Voices coordinator, Katie Whittle, are currently working with the task force participants and their local bleeding disorders organizations to create videos for both the Voices campaign and their local communities. ■ ■



Media Task Force

Travis Albright

Veronica Idoate

Matthew LaBolle

Peter Marciano

Kevin Parker

Nicholas Resier

Ryan Shorosky

Leland Smith

Jose Tavarez

Jozef Zwier

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In Memoriam

On July 9, 2011, Charles (Chuck) R. Skopinsky passed away from complications following a liver transplant at age 40. He is survived by his wife, Vicki; young son, Robert; and father, Bernard, as well as aunts, uncles, cousins, and many friends.

In the hemophilia community, Chuck was an active member and supporter of HFA. A Blood Brother at BDAST, he delighted in outings with his hemophilia brothers like the snowmobile trip. Chuck took his responsibilities to his fellow brothers seriously by encouraging older adults to infuse themselves and be independent. He was a friend to many across the country, actively using Facebook and the Blood Brotherhood Online Forum to connect, check in and support others. At HFA, Chuck served as a board member. His motto was, "whatever you need, anything I can do." He is greatly missed.

Indemnity: Indemnity insurance for health-care has become less and less common with the arrival of MCOs. It reimburses you (at some predefined percentage) for expenses incurred after you have fulfilled your deductible. Reimbursement for the year was traditionally limited to a certain amount as well. **The upside?** You can see any doctor you want. **The downside?** You may have a high deductible. Also, you generally have to file your own claims. And it's up to you to figure out how much your care will cost and if you can afford it.

TRICARE: TRICARE is the healthcare program for military personnel, military retirees, and their dependents. It offers many of the types of coverage described in this article and a few more. You'll want to study your options carefully before selecting which TRICARE coverage to use. As with the other types of insurance listed here, sometimes the higher premium is the better deal for you in the end. ■■

For more information on these options, check out these websites:
www.tricare.mil or <http://www.kff.org>

Capitation An amount paid by your insurance company to your provider, for which the provider agrees to treat all members of the insurer.

Coinsurance A percentage of the cost that you may have to pay. You might have to pay 20% of the cost of a surgery in addition to your co-pay; the insurance company would pay the other 80%.

Co-pay (or co-payment) The amount that you pay before your insurance pays for a doctor visit or other service. You might pay a \$45 co-pay for a doctor visit.

Coverage limits Some policies only pay for healthcare up to a certain dollar amount. You might be expected to pay any charges in excess of this amount. Coverage limits can be either annual or lifetime coverage maximums. Lifetime coverage limits have been lifted with healthcare reform, but annual coverage limits are still allowed until 2014.

Deductible The amount that you pay out-of-pocket before your insurance pays its share. You might have to pay a \$500 deductible each year before your healthcare is covered.

Exclusions Not all services are covered. You are expected to pay the full cost of services that are not covered by your plan.

Explanation of benefits A document that you might receive from your insurance company explaining what was covered for a medical service and how the payment amount and patient responsibility amount were determined.

In-network provider A healthcare provider on a list of providers selected by your insurance company. A provider who is on your network.

Out-of-pocket expenses Expenses you pay for medical care, such as co-pays and deductibles.

Out-of-pocket maximums The maximum you have to pay toward medical expenses yourself for your plan. Many plans have out-of-pocket maximums per person and then a larger amount that is the maximum for family.

Premium The amount the policy-holder or his sponsor (e.g., an employer) pays to the health plan to purchase health coverage.

Prior authorization A certification or authorization that an insurer provides prior to medical service occurring. Obtaining an authorization means that the insurer is obligated to pay for the service, assuming it matches what was authorized. Many smaller, routine services do not require authorization.

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