

PEN

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The App of Your Eye

Which bleeding disorder app is best for you?

Aaron Craig and Laurie Kelley

Smart phones—just how smart are they? If you own one, you already know it can store phone numbers, take photos and videos—plus connect you instantly with Facebook, YouTube, and Twitter. You can shop online, play games, or find a particular pizza joint in Hoboken, New Jersey, and be guided there. You can check all your emails at home, and text your kids about doing their homework while you're at the office. Apps are so useful that about a billion people can't imagine living without one!¹

And now families with bleeding disorders are finding out just how useful smart phones and apps can be in managing their disorder: smart phones can help you track a bleed, scan your factor lot numbers, and keep your clinicians updated on your health or your child's.

This is important for our community because in our current insurance climate, insurance companies (payers) will increasingly request proof of your factor usage. Healthcare costs have escalated, and payers are under the gun to cut costs.

What's the most expensive part of your bleeding disorder treatment? Factor. How many of us actually log in and record our bleeds, dates, number of units of factor, brand, and lot

number? Not many. And how many of us share this information with our own hemophilia treatment center (HTC) medical professionals—the people monitoring our well-being and care? Again, not many. We've become so good at infusing independently at home that we often forget to let our HTC know how we're doing unless something goes wrong. Are we prepared to give our payers detailed information if requested about our treatment plan and factor usage—factor worth millions of dollars—in a readily accessible form?

Phone applications, or apps, have been developed specifically to help you record your vital bleeding disorder information and to make this data easily available, easy to review, and easy to transfer. No longer do you have to peel off a sticky label, scribble in a notebook, or enter numbers into your spreadsheet. Click, click, click, send, and you're done. How do you pick one of the many apps to meet your needs?²

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1. Charukie Dharmaratne, "Is the World Ready for Mobile Payments?" *TechMunch* (Feb. 15, 2013), leishman.co.uk/2013/02/friday-techmunch-is-the-world-ready-for-mobile-payments (accessed Mar. 6, 2013). 2. All information about the apps reviewed here is current as of PEN's publication date, and may change over time as updates become available.

welcome

Laurie Kelley

BY THE TIME I FIGURED OUT WHAT AN “APP” WAS, THERE WERE already thousands of apps to choose from and new versions of the iPhone for downloading them. Indeed, I walked into the Apple store to upgrade my phone last year, and the genius barista (remember it’s called a genius “bar”) gathered everyone in the store to gaze at my iPhone in star-struck wonder. It was old, a classic, Generation 1... *only six years old*. Ouch.

It’s hard to keep up with technology, even when we know it can help us. But it’s also hard to keep up with bleeding disorder treatments amid the bustle and demands of everyday life. I’m intrigued by the new apps available just for recording bleeds and infusions. Some are very clever and can help you get organized. They can foster better dialogue with your treatment center and facilitate data sharing. As you become more and more independent of your HTC for regular infusions, an app is a great way to save time and money and also continue to give your HTC the treatment info needed to monitor your health progress.

For this issue, we’ve invited Aaron Craig, who created an app for the bleeding disorder community, to walk us through the various apps designed to make our lives easier. Check out our review, and learn about them all.

So what apps do I have? Not one for hemophilia anymore, as my son is grown. I have one for fitness; Amazon.com and Kindle; Star Walk (for learning the constellations—excellent, by the way!); Facebook; Twitter; Ticketmaster (to locate those Doors tix); a flashlight app (never used—it just looked cool); and all the major airlines to check my flights. Not too many, but I know that some people have hundreds of apps, mostly games involving bunnies, aliens, and angry birds. My ideal app? One that will help me get my PEN articles turned in on time! ☺

inbox

I ENJOYED THE ARTICLE IN PEN [“THE JOBS JOURNAL,” Nov. 2012] about the young men and how they decided what careers to pursue. I am looking forward to the second part on young men who did not go to college first. Our son is 19, and this information is both encouraging and informative. Thank you for all you do for our community.

John Wulf
NEW YORK

Ed. note: Look for part 2 of the Jobs Journal in the upcoming November issue of PEN.

MY SON HAS SEVERE HEMOPHILIA A. WHEN THE DOCTOR diagnosed him and handed me a script for factor and sent me on my way, I couldn’t find a pharmacy that had it. I had no way of knowing how to get his medicine, and the doctor didn’t give me any information. So I looked around and found your book, and it saved us. Now I order your books when I move around and make sure they are in the library. I owe a lot to you. Thank you!

Norma Atherton
ILLINOIS

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PARENT EMPOWERMENT NEWSLETTER MAY 2013

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Cubixx: An Innovative Way to Reduce Factor Inventory Costs at HTCs

No doubt about it. This is an exciting time for the hemophilia community. New factor products are nearing the end of the pipeline. Some of these new medications will offer improved benefits, such as longer half-life, that will enhance the quality of patients' lives. Those benefits are easy to see. But other innovations have already been introduced, providing benefits that hemophilia patients may not easily see. The Cubixx consignment system from ASD Healthcare is one of those innovations.

Cubixx is a storage and monitoring system designed to help hospitals track inventory of biological drugs such as clotting factor concentrate. Cubixx provides custom-made refrigerators to store inventory; inside, each box of product is

tagged with a radio-frequency identification tag (RFID),¹ which contains product data—like a barcode on a product scanned at the grocery checkout. But with an RFID tag, no one needs to scan each box; it is scanned automatically as it is removed from inventory. For factor, the Cubixx system tracks brand, IU, lot number, expiration date, and individual serial numbers. Tracking serial numbers documents a product's *pedigree*, or where it has been. This lets manufacturers, distributors, and sellers follow each vial of factor, from manufacturing plant to patient's bloodstream.

Cubixx works on a consignment model. In other words, you pay for only what you sell: ASD Healthcare provides product to healthcare facilities such as HTCs, blood banks, and hospitals, and bills them only for the product actually used by patients. Typically, healthcare facilities must purchase the factor they hope to sell, which can get expensive. Cubixx reduces the need for these facilities to purchase and hold expensive factor inventories that may or may not be sold. And this also helps eliminate the added expense of lost, stolen, or expired products.

Sounds like a great business model, doesn't it? But how does this benefit the hemophilia patients who depend on healthcare facilities?

Factor distribution, like all biological product



Chris Flori of ASD Healthcare

distribution, presents unique logistical challenges. Factor requires "cold-chain" handling (meaning it must be refrigerated in transit) and is very expensive. And factor has no unique identifier by the National Drug Code for each assay level. In other words, the drug code for a 250 IU vial is the same as the code for a 400 IU vial. It's tough to track detailed assay information on each vial, as it is sold from manufacturer to distributor to HTC to patient, when the codes assigned by the government don't provide enough information. In developing Cubixx, we created a system that reduces three challenges that hemophilia facilities face: economic, operational, and clinical.

Economically, the benefits of Cubixx consignment inventory are significant. Paying for products only when they're used, while still having access to all assay sizes of products, provides savings for healthcare facilities. They won't incur freight expenses or financial losses due to expired factor or unsold assay sizes. When the healthcare facility saves money, more money is freed for patient programs and needs. Rather than first purchase and hold expensive inventory, facilities might choose to redirect their money to camp funding, staff salaries, educational materials, and family information days.

Operationally, Cubixx does the heavy lifting for reorders: it produces purchase orders and manages day-to-day factor inventory. This takes administrative

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1. Radio-frequency identification (RFID) is a wireless non-contact system that uses radio-frequency electromagnetic fields to transfer data from a tag attached to an object, for the purposes of automatic identification and tracking.

Using Apps When You Have an Inhibitor

If you live with inhibitors, you know how complicated life can be. You or your child may be on several different medications and have a demanding treatment regimen. You may have several appointments a week at your hemophilia treatment center (HTC). On top of that, you have all the other responsibilities of parenthood.

The mobile apps profiled in this issue of PEN are designed to help organize your life and make it easier to track doctor appointments, treatments, bleeds, and medications. How well do they work if someone in your family has an inhibitor?

Benefits of Mobile Apps

For years, many parents, caregivers, and patients have tracked factor usage and bleeds on computer spreadsheets or with pencil in a paper logbook. These methods work well for many people, but they have limitations. Mobile apps are a more convenient method for keeping track of bleed data. These software applications are designed to run on smartphones, tablet computers, and other mobile devices.

The benefits? Tech-savvy teens and young adults (who often seem to be attached to their cell phones) might prefer to use apps to track their info rather than fill out an entry in a logbook or use a computer. Plus, data on bleeds stored electronically is easier to transmit to a doctor quickly in an emergency.

Some health insurance companies require detailed information about infusions: time, date, brand, lot number, bleed type, and dosage. A mobile app can help you keep track of all this info and make it easier to share with caregivers. And if you're away from home, it's easier to enter or scan product data and bleed info into a mobile app than use a logbook or spreadsheet. Some apps also allow you to set reminders for appointments or treatments as well as record factor usage. Newer apps allow a user to track not only factor usage, but every aspect of living with a bleeding disorder.

Several apps allow users to set up multiple patient profiles—a benefit for parents and caregivers. And this way, older kids can take part in their own care and enter their bleed and treatment info on their own.

Will an App Work for You?

Novo Nordisk's HemaGo app was designed to be especially helpful for patients with inhibitors, according to the company's press release. It was developed to improve communication



between hemophilia patients and their caregivers. Because treatment for inhibitors can be so complicated, the app makes it easier to keep track of all the details.

The HemaGo app allows users to record information on all medications that patients are using, including over-the-counter meds. This gives doctors a better overall picture of the patient, which can help prevent possible negative interactions. HemaGo can also record how much factor is used and the reason for each infusion.

Another useful feature of HemaGo is that it lets you record other data about a bleeding episode besides just the basics. What was the level of pain? How did the bleed affect work, school, or daily life? Where was the bleed, and how long did it last? This info is valuable for evaluating treatment regimens.

The data that you enter into the HemaGo app syncs with Novo Nordisk's website, called Changing Possibilities in Hemophilia,¹ and can be shared with doctors or healthcare teams. You can use the app to create customized reports through Changing Possibilities, and then print out or email the reports to your healthcare team. HemaGo also allows you to set up reminders on your phone for appointments or treatments, or log prophylactic treatments.

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1. The company's website states that Novo Nordisk does not have access to patient-specific information. The company's access is restricted to generic information ("de-identified") in which the data has been stripped so that the individual source cannot be identified, in accordance with Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy and Security Rules. For info: www.novonordisk-us.com/documents/article_page/document/disclaimer.asp.

Richard J. Atwood



Wear Your ID PROUDLY



Yes, wearing your medical identification can be a hassle. But not wearing a medical ID can be life-threatening.

Here's the often-repeated mantra: if you have a bleeding disorder, always carry your medical identification. Your healthcare providers emphasize this sage advice because not only will it protect you, but it will also improve their ability to provide proper treatment. I was curious to know when this advice was first offered, so I checked the medical literature and found a long, fascinating history of medical identification for bleeding disorders.

Tattoos

In the April 23, 1898, issue of the *British Medical Journal*, English physician S. J. Ross described the case of a 28-year-old man with hemophilia who did not admit to a history of hemo-

philia until three days after an abscess on his swollen right elbow was excised, causing him to blanch from the hemorrhage. This prompted Ross to suggest that anyone with hemophilia should have the term *hemophilic* or *bleeder* tattooed on their skin.

Three weeks later Clinton Dent, a London surgeon, responded in the same medical journal that obtaining consent to tattoo would be difficult, and that the actual tattoo punctures would likely “cause trouble,” probably uncontrollable bleeding. Instead, Dent suggested that patients wear a small label around their necks noting their condition—although he was not sure they would comply. Mr. Ross had the last word two weeks later, commenting that the patient would remove any label, and that tattooing in a single session would not cause trouble.

Clothing Labels

In 1934, Philadelphia physicians Harold Jones and Leandro Toncantins reported in the *Journal of the American Medical Association* on the treatment of hemophilia. They recommended that people with hemophilia always carry a document stating their condition, for proper

protection if rushed unconscious to a hospital or doctor's office. The identification could be sewn to a prominent part of the inner clothing.

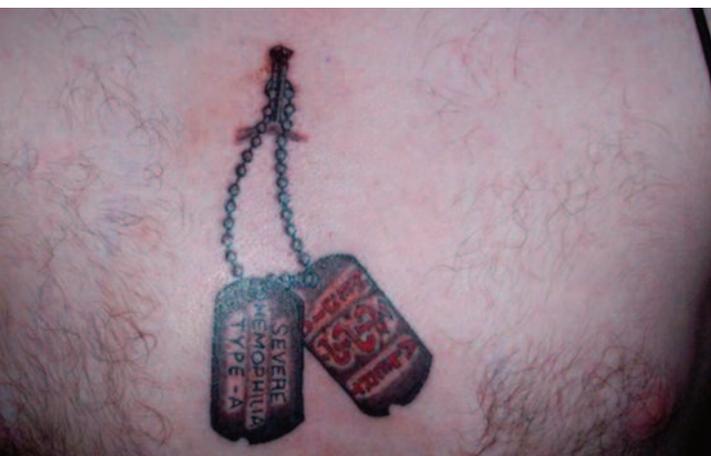
Cards, Emblems, Microfilm

In 1954, the Medical Research Council in London announced a new “explanatory card” to be carried at all times by patients with hemophilia. The card contained a statement that the bearer had hemophilia and was under the supervision of a named physician and hospital. Besides stating to contact the hospital in case of injury or bleeding, the card contained information about transfusion and blood group. The patient's practitioner had to contact a hemophilia reference center before a card could be issued to the patient, and a copy was filed with the Medical Research Council to form a hemophilia registry in England.*

By 1962, the identity card used by everyone with hemophilia in Sweden included the patient's photo. The card, written in Swedish and English, listed the patient's name, address, diagnosis, blood group, proper treatment, and doctor's contact information.

In Egypt in 1977, all registered patients with hemophilia received a hemophilia card and a metallic badge so their diagnosis would be easily identified.

By the 1990s in the US, a hemophilia ID card with medical information embedded in microfilm in one corner, sometimes with a small magnifier embedded in another corner,



Daniel LiVolsi

Creative 21st-century tattoo: Daniel LiVolsi had his medical info tattooed on his chest

a project share story



PROJECT
SHARE

It's time to give back

Zoraida Rosado

Another Banner Year

Project SHARE had another banner year providing blood-clotting medicine to developing countries. In 2012 we donated 5.6 million IU of factor, valued at \$5.6 million, to 34 countries. Through these donations, we were able to provide relief to hundreds of people with bleeding disorders. We also donated NovoSeven, valued at \$427,000, to 6 countries. In a major contrast with past years, most of our donations in 2012 went to Latin America and the Caribbean.

SHARE visited Zimbabwe in December—our fourth trip there. Laurie Kelley also visited Zambia, making the first official visit by a hemophilia program there. She met with a newly formed hemophilia organization and submitted an assessment report to the World Federation of Hemophilia (WFH). SHARE provided \$1,000 in funds to help the Haemophilia Foundation of Zambia (HFZ) create business cards and letterhead stationery.

Our deepest thanks go to all who have donated factor to Project SHARE, especially those who donated in memory of a loved one. Project SHARE is also grateful for the continued financial support of our corporate partners in 2012:

- ASD Healthcare
- Baxter Healthcare Corporation
- CSL Behring
- New England BioLabs
- Novo Nordisk Inc.
- Octapharma



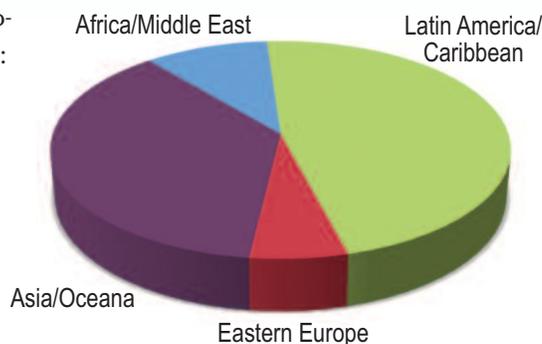
“Thank you so much for all the support you give our hemophilia patients.

You have saved many lives.”

—Agnes Kisakyé

Hemophilia Foundation of Uganda

2012 Factor Recipients by Region



Richard's Review...from page 5

increased the amount of information on the card.

Today's Options

People with bleeding disorders are fortunate to have a variety of medical identifiers today. Remember, first responders tend to look for emblems such as the medical bracelet, while emergency room staff search wallets for identification. The MedicAlert® emblems that now come in a variety of styles are universally recognized and provide basic information. The ATHNready wallet card contains a flash drive that can be plugged into a computer to provide detailed information on the patient, medical condition, and recommended treatment. Medical info can also be attached to a seat belt, automobile sun visor, or backpack; this kind of backup info helps assure that medical staff are alerted.

For over 100 years, the message has not changed: *always carry medical identification about your bleeding disorder.* What has changed is the way that information is packaged. Contact your HTC or your chapter to get the most appropriate medical ID.

** In England at the time, hemophilia reference centers were what we now call hemophilia treatment centers. England began its organized network of HTCs long before there was federal funding in the US. A national English registry for hemophilia was established, but this was not the first—Sweden began its registry in the 1750s.*

For more info on medical identification and a list of references used in this column, please visit www.kelley.com/newsletters.



Non-Pharma Apps and Websites

MicroHealth

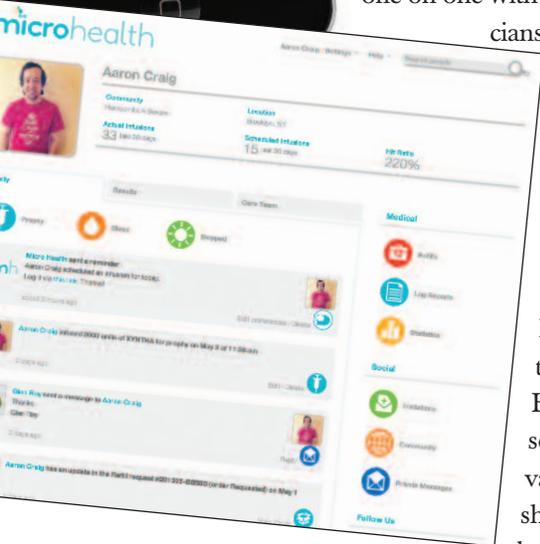
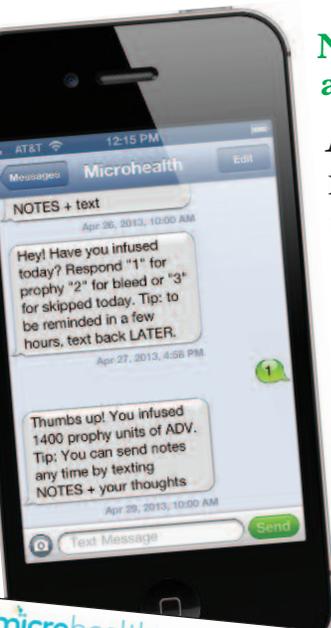
Hemophilia patient Aaron Craig and Columbia University scientist Marc Lara recently launched a start-up company called MicroHealth. The first release of the company's app (also called MicroHealth) for the hemophilia community is a HIPAA-compliant³ platform that works on any cell phone, via interactive text messages, and online. The app is designed to track treatment progress, and to connect one-on-one with caregivers and clinicians via a private social health network.

You can easily exchange messages and share your infusion log electronically with designated members of your healthcare team. And through MicroHealth's Community section, you can gain valuable insights and share knowledge with hemophilia community

members who are registered, by asking or answering questions. As with all other logging apps, MicroHealth is designed to help you make better treatment decisions.

Patients can sign up on their own or by doctor recommendation. Parents can create family accounts to manage their children's health. Patients receive personalized medication reminders that adjust to their specific care plan (for example, prophylaxis, on-demand, or immune tolerance induction [ITI]), and they can order medication refills from their pharmacy through MicroHealth. Clinicians using the platform's control panel can see at a glance which patients are reporting bleeds or are not following treatment regimens properly, thus

This article represents an overview of smart phone apps currently available in US app stores. It does not take into consideration other products that might be in development or testing.



helping to prioritize valuable clinical time. Nurses and doctors can also make interventions (such as requesting a follow-up appointment) directly from the platform.

MicroHealth

Benefit: Works on all mobile phones (basic handsets and smart phones) via text messaging.

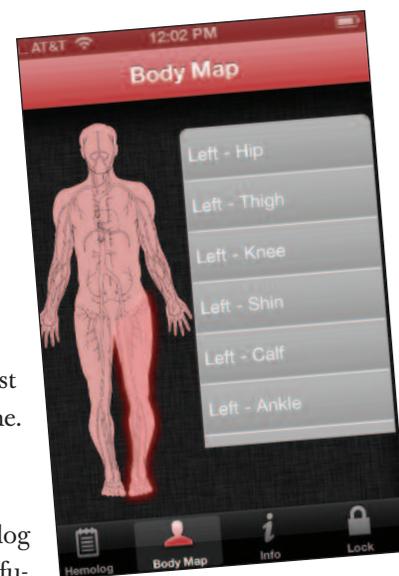
Disadvantage: Smart phone app will not be available until later this summer.

Get it here: www.microhealth.org

Hemolog

Hemolog, one of the first hemophilia apps to be released, is the brainchild of visionary hemophilia patient Michael Schultz. Hemolog provides an easy way to log bleeds by simply touching the bleed location on an onscreen body map. No need to write in the location; just touch the image, and you're done. This feature was later copied by several hemophilia app makers.

But one drawback to Hemolog is that it's hard to share your infusion log with your HTC. Sharing works only when you send the log within the text of an email; you can't export the log to a PDF or Excel file, which would make it easier to share. In the past year, Hemolog has announced that it will not make updates to the app, and instead has encouraged users to join MicroHealth.⁴



Hemolog

Benefit: Very easy to use.

Disadvantage: Difficult to export and share data.

Get it here: itunes.apple.com

Advoy

Originally developed by Baxter Healthcare Corporation, Advoy is now owned and operated by the American Thrombosis and Hemostasis Network (ATHN), a nonprofit dedicated to collecting and collating patient data nationally. ATHN uses the patient data collected from Advoy to analyze bleeding disorder treatment outcomes. So while you record your bleeds and factor information into the app for your own

3. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) Privacy Rule provides federal protection for personal health information held by "covered entities," such as hospitals and home healthcare companies, and protects patients' rights regarding that information. *HIPAA compliant* means that any company, organization, or entity that handles protected health information must ensure that all the required physical, network, and process security measures are in place and followed. 4. See vimeo.com/48281391. This video is a collaboration between MicroHealth and Hemolog. Michael Schultz, Hemolog's creator, has stopped development of Hemolog and now encourages users to join MicroHealth.



purposes, your info is being combined with other data at ATHN for research purposes—but ATHN guarantees your personal privacy.

One benefit of using Advoy is that more than 120 HTC's are connected to the ATHN system,⁵ making it easy to share your data with your HTC if it is registered and affiliated with ATHN. Advoy is available on iPhone, iPad, iPod touch, and the web. There is no Android version available. Getting access to Advoy can be a bit

challenging at first. Your HTC must register you for the app before you can use Advoy, so if your HTC does not use ATHN Advoy, neither can you. But once you access the system, it's relatively easy to use.



Advoy

Benefit: Integrates with ATHN dataset to be used for clinical research analysis.

Disadvantage: Your HTC must use the app and register you.

Get it here: itunes.apple.com

Industry Apps and Websites

The following apps were created by individual factor manufacturers. With the exception of the CSL Behring app that can be used only with that company's product, most manufacturer apps can be used for any bleeding disorder product.

Beat Bleeds

Beat Bleeds is owned and operated by Baxter Healthcare. The design is user friendly, with pleasing graphics: instead of just showing data points and lots of spaces to enter information, this surprisingly artistic app incorporates high-quality pictures of people on each screen, bringing life to the user experience. Beat Bleeds operates under the mantra that less is more. Its primary function is to record bleeds; it does not record infusions, lot numbers, or units infused. The app is smooth and clean, and it works well to log bleeds.

Beat Bleeds offers a second major function: "push notifications" are little messages that remind users when to do (and record!) their prophylaxis infusions. Beat Bleeds also encourages users to set up their *estimated* annual bleed rate (ABR) to compare to their *actual* ABR. Your ABR is the number of bleeds you have during the course of a year. The goal is to try to lower the number of bleeds you experience in a year by first making you more aware of how many you are actually having.



Beat Bleeds

Benefit: Crisp, clear design; photos bring life to the app.

Disadvantage: Minimal functionality; can only record bleeds.

Get it here: itunes.apple.com

5. <http://www.athn.org/node/211> (accessed Apr. 10, 2013).

Compare the Apps!

Name	Source	iPhone app	Android app	iPad app	Text logging	Web profiles	Family profiles	Snycs to web	Non-smart phones	Tracks bleeds
Advoy	ATHN	✓	–	✓	–	✓	–	✓	–	✓
Beat Bleeds	Baxter Healthcare	✓	✓	✓	–	–	–	–	–	✓
MyCubixx	ASD Healthcare	✓	✓	✓	✓	–	–	–	✓	✓
FactorTrack	Bayer HealthCare	✓	✓	✓	–	✓	–	–	–	✓
HeliTrax	CSL Behring	✓	–	✓	–	✓	–	✓	–	✓
HemaGo	Novo Nordisk	✓	✓	✓	–	✓	✓	✓	–	✓
HemMobile	Pfizer Inc.	✓	–	✓	–	–	✓	–	–	✓
Hemolog	Michael Schultz	✓	–	–	–	–	–	–	–	✓
MicroHealth	MicroHealth	–	–	–	✓	✓	✓	✓	✓	✓



HemMobile

HemMobile is a logging app created by Pfizer Inc. The sleek, high-contrast design is outstanding. As you log information, the app displays all infusions and bleeds on a graph. It's relatively easy to see how *not* infusing on a particular day could have caused a bleed the next day. Although the app is available for anyone to use, regardless of product, the smart phone scanning functionality is exclusive for people who use Pfizer's products; scanning allows you to scan IU, lot number, and expiration date. HemMobile also

allows for family profiles, and lets parents log in for multiple children within the single app. But when you start to add more than one child, the app becomes slightly awkward to handle. HemMobile is not available on Android and does not offer a web portal. But the app does allow your information to be saved via Apple's iCloud for retrieval in case of phone loss, breakage, or switching phones.

HemMobile

Benefit: Scanning lot numbers, expiration dates, and IUs (Pfizer patients only).

Disadvantage: Can't connect to your healthcare provider.

Get it here: itunes.apple.com



HemaGo

HemaGo is provided by Novo Nordisk and is loaded with features. It has iPhone and Android versions, and everything syncs to Novo's Changing Possibilities

website. All information on HemaGo also syncs with the ATHN database. HemaGo offers family profiles so that parents can log on and manage multiple children from the same app.

When logging a bleed, you can monitor pain scales directly from the app. HemaGo also offers quality-of-life logging, allowing you to rate your overall pain and health on scales of 0-10 and 0-100, respectively.

Even though the app offers a lot once you are logged on, when compared to the rest of the apps the registration process is relatively long. It requires registration to the Changing Possibilities website; and once that is set up, users must reenter much of the same info into the app. HemaGo offers much and gives the patient the most options when compared to the other apps. But with more options comes greater complexity. Detail-oriented, patient people: this is the app for you.



HemaGo

Benefit: Many functionalities and web portal.

Disadvantage: Registration is time-consuming.

Get it here: itunes.apple.com

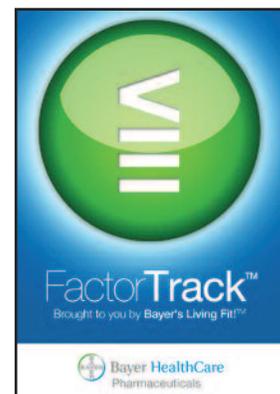
FactorTrack

FactorTrack, offered by Bayer HealthCare, was the first hemophilia logging app to emerge from a pharmaceutical company. Bayer was one of the first pharmaceutical companies to launch any iPhone app, which made Factor-

Track a game changer in the bleeding disorder

community. Although FactorTrack offers the ability to create a web profile for logging on its website and also a profile for logging via your smart phone, the two profiles do not sync with one another. So if you have an app, data will not automatically be updated to the website. If your phone is broken, lost, or stolen, any data stored only on your app will not be retrievable.

FactorTrack allows you to view your infusions, bleeds, and skipped days on a month-by-month color-coordinated calendar. The



Tracks infusions	Tracks lot number	Connects to friends	Connects to HTC	Connects to pharmacy	Offers refill reminders
✓	✓	-	✓	-	-
-	-	-	-	-	-
✓	✓	✓	✓	✓	✓
✓	✓	-	-	-	-
✓	✓	-	✓	-	-
✓	✓	-	✓	-	-
✓	✓	-	-	-	✓
✓	✓	-	-	-	-
✓	✓	✓	✓	✓	✓

app also allows you to export your information via email in text format to send it to your healthcare provider. FactorTrack helps users stay on track with infusions by sending push notifications whenever it's time for an infusion.

FactorTrack

Benefit: Simple design; easy to use.

Disadvantage: Phone app logs do not sync to FactorTrack website.

Get it here: itunes.apple.com

HeliTrax

HeliTrax is operated by CSL Behring and was built in collaboration with the ATHN network. So everything that is logged on HeliTrax is automatically synced to ATHN. Unique to HeliTrax is that you must be using CSL Behring's



product in order to access the app. HeliTrax offers users the ability to log infusions, manage inventory, and view logs. It uses a body map like Hemolog's: touch the map to define where your bleed is located. The app also offers a web version, to which all information from the phone app is synced.

HeliTrax

Benefit: Syncs to HeliTrax website and ATHN.

Disadvantage: Only for CSL Behring products.

Get it here: itunes.apple.com

Go Paperless: Which App for You?

Writing your infusion information on pieces of paper is cumbersome. It isn't data friendly, either. Seeing trends in your bleeding patterns or locating a particular vial of factor used in the past can be difficult when you have to flip back through pages and pages. Peeling and sticking labels is slightly better, but your HTC still doesn't get your valuable bleeding pattern data for research and to monitor your health. Maybe this is why so many parents and patients don't record *any* infusion or bleed information!

The hemophilia community is fortunate to have so much technology at our fingertips to help us manage

our health. The apps and websites listed here were designed to help our community, and what's great is that the choice is *yours*: if you want to use an app, you decide which platform works best for you. Take some time exploring the different apps with your family. Learn how this new technology is helping to shape the future of hemophilia care around the world. @

Aaron Craig is a co-founder of MicroHealth (www.microhealth.org), a digital health tool for the hemophilia community. He graduated from the King's College in New York City with a degree in politics, philosophy, and economics, with a concentration in media. He was an intern at Bayer HealthCare in the Hemophilia Leadership Development Program. He is also a passionate, avid filmmaker and founded the film production company We Are Films (www.wearefilmsny.com). Aaron has severe hemophilia A, but that doesn't stop him from living life to the fullest!



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From Minibar to MyCubixx

Laurie Kelley

Ever use a minibar in a hotel? Some have sensors that automatically charge you for whatever you remove. The charge is sent electronically to your room bill, which you see when you check out. The lowly hotel minibar is the inspiration for MyCubixx,* perhaps the most unique technology so far for logging your factor and tracking bleeds.

MyCubixx is a mini refrigerator that is equipped with radio-frequency identification (RFID) technology, designed to track factor usage as well as bleeds. Each box of factor that is placed inside the refrigerator has an RFID tag; when you remove a box, information such as lot number, IU, and date of use is logged automatically by the RFID reader in the fridge. To unlock the mini fridge and access the factor, you must enter information about your bleed on a keypad, using a graphic of the human body.

Easy and simple...and free. MyCubixx is provided free of charge to customers who purchase their factor from ASD Healthcare. ASD also provides the RFID tags in the factor boxes for use with the MyCubixx system. The information you enter goes to a secure website. From there, you can print out your history of product usage and bleeds. You can also arrange to have the data sent electronically to your HTC. And there's a mobile app that allows you to log in factor usage and bleeds when you're on the road. You can use MyCubixx with multiple children with bleeding disorders, and track them all separately.

LA Kelley Communications conducted a series of focus groups with 40 patients and their families last fall. We divided participants into four groups, with ten participants each, and then asked parents and patients in different age groups to test MyCubixx and give feedback. We learned a lot about how people feel about logging in factor and tracking bleeds in general. Most surprising was the number of parents and patients who either log in everything by hand, or who do not log information at all! Here's what we learned:

- Most participants agree that logging in factor and bleed data is inconvenient.
- Parents of young children most often log in bleeds and treatment by hand.



- The highest percentage of participants using smart phone apps were patients in the over-18 age group.
- Participants who do not currently log bleeds believe that technology like RFID will increase their compliance in logging factor and bleeds.
- Patients tend to believe that technology like RFID is a great way to manage and log bleeds and treatments; families with children with bleeding disorders tend to view the technology as a good way to teach their children compliance.

Of the bleeding disorder families who log, most do it by hand using scraps of paper, binders, or notebooks, and some use spreadsheets on their home computers. Very few have switched to mobile apps. Data recorded locally or by hand cannot easily be analyzed for patterns; infusions that are not logged cannot be tracked for recalls or effectiveness. In an effort to control skyrocketing healthcare costs, the insurance industry may increasingly require patients to log infusions, including data on IU, number of vials used, lot numbers, and brand. RFID technology, such as MyCubixx, might help us comply with payers who request bleed logs before we order more product, while electronically and automatically removing the burden of logging. Think of it the next time you use a minibar!

*MyCubixx and Cubixx are both provided by ASD Healthcare. MyCubixx is a factor inventory and bleed logging program for individual use, in the form of a mini fridge. Cubixx is a factor inventory consignment program for HTCs. For more information, see our As I See It column in this issue of PEN.



headlines

PHARMA

CoRe Conversations

Biogen Idec Hemophilia is providing these educational teleconferences for the bleeding disorder community:

- Setting Educational Expectations: establishing clear goals and routines for school-age children with bleeding disorders. (July 16, 8:00 pm EST)
- Understanding the Value of Genotyping: how genotyping offers interesting info that may lead to greater understanding of hemophilia. (Sept. 17, 7:00 pm EST)

Why this matters: Educational teleconferences are a great way to keep informed on current information on bleeding disorders without having to travel.

For info: www.biogenidechemophilia.com/events



Copay Help

Patient Services, Inc. (PSI) and Bayer HealthCare jointly run the Kogenate® FS Co-pay/Co-insurance Assistance Pilot Program, funded by Bayer to help qualified Kogenate FS patients with their out-of-pocket payments for the drug. Certain restrictions apply.

Why this matters: As insurance reform takes place, patients may see out-of-pocket costs associated with their healthcare coverage.

For info: 800-288-8374

First Long-Lasting Factor Becoming a Reality

The US FDA has accepted Biogen Idec's Biologics License Application (BLA) for marketing approval of recombinant factor IX Fc fusion protein (rFIXFc) for treating hemophilia B.

Why this matters: rFIXFc is the first product candidate in a

new class of long-lasting clotting factor therapies being developed for hemophilia B.

For info: www.biogenidec.com

HOME CARE

REBUILD Your Health



REBUILD, a new physical therapy program, helps patients, physicians, physical therapists, and health insurers manage the complications and costs of hemophilia-related joint damage. REBUILD works with HTC's, physicians' offices, and qualified local therapists to oversee a customized physical therapy plan for each patient. Components include expert hemophilia care plan

oversight; trained and locally based physical therapists; routine updates and care coordination with the treating physician; access to advanced physical fitness and training technologies; motivational drug therapy adherence; and local community training and education. **Why this matters:** About 30% of hemophilia patients don't receive care from an HTC.

For info: 866-44-BIORX
rebuild@biorx.net
www.biorxhemophilia.com

WORLD

Chris Bombardier, age 27, became the first person with hemophilia to summit Mt. Aconcagua (highest peak in the Americas) in February after a strenuous 12-day hike. This is the second of the "Seven Summits" Bombardier wishes to conquer to raise money and public awareness for hemophilia causes. **Why this matters:** Unique physical activities like this climb help to shatter the misconception that people with hemophilia are fragile.

For info: www.saveonelifenet.net



NONPROFIT

MentorConnect: Helping New Parents

National Hemophilia Foundation's MentorConnect is a new mentoring program for parents. The goal is to decrease social isolation and increase social support for families of newly diagnosed children. Experienced parents of children with bleeding disorders will serve as mentors to newly diagnosed families, contacting them monthly by phone and twice monthly via email.

NHF is currently recruiting participants. **Why this matters:** Experienced parents of children with bleeding disorders often have unique and practical info that may be unavailable through traditional support venues such as HTC's and online forums.

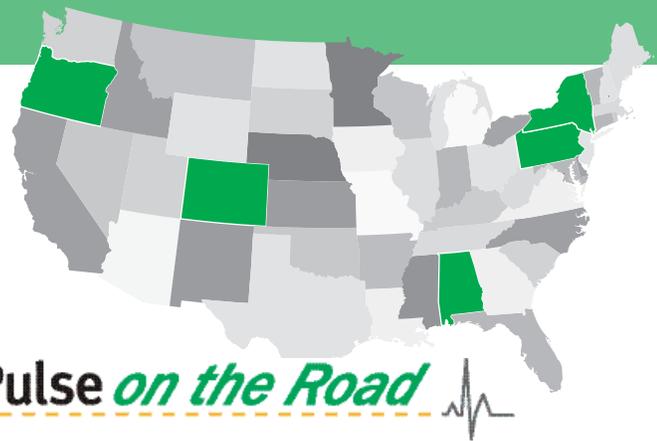
For info: Sonia Roger
sroger@hemophilia.org



LA KELLEY COMMUNICATIONS

Pulse on the Road to Visit Six States

Pulse on the Road (POTR), a comprehensive, hands-on insurance symposium and workshop, is traveling to six states in 2013: New York, Colorado, Alabama, Pennsylvania, Oregon, and one of Coalition for Hemophilia B's regional meetings (TBD). POTR offers an overview of the Affordable Care Act and the importance of being able to choose your own insurance, and provides a practical workshop on choosing the best insurance policy. Funded by Baxter Healthcare Corporation and run in cooperation with NHF.



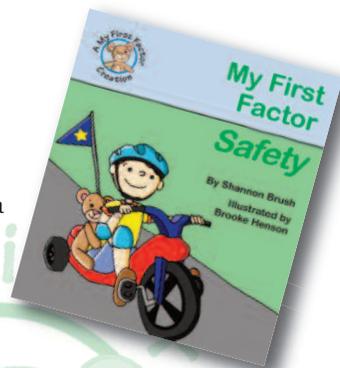
My First Factor: Safety

The charming series of toddler books for youngsters with hemophilia continues with a new title!

My First Factor: Safety introduces the concepts of being careful and wearing safety gear. Written by Shannon Brush, mother of a child with hemophilia.

Funded by Bayer HealthCare.

To order: www.kelleycom.com



SCIENCE

Gene Therapy Moves Closer to Trials

A factor VIII gene therapy program for hemophilia A from University College London and St. Jude Children's Research Hospital has been licensed to BioMarin of California. The company expects to initiate proof-of-concept human studies by the end of 2014. **Why this matters:** Gene therapy research in hemophilia is back on track after losing funding and direction following the 1999 high-profile death of a US patient (who did not have hemophilia) in a gene therapy trial.

Source: globenewswire.com
(Feb. 21, 2013)



As I See It... from p. 3

burden off the healthcare facility. And the facility can log into the Cubixx website to view its inventory of products anytime.

As the largest distributor of factor in the US, we have access to commercial product and 340B product in a breadth and depth that gives clinicians the widest possible selections of factor brands and assay sizes at their fingertips. This Cubixx benefit gives facilities instant access to more product options to meet a wider range of their patients' needs.

ASD Healthcare has a 20-year history of serving the hemophilia community. We're committed to innovative solutions for the healthcare facilities that care for hemophilia patients. The Cubixx consignment system is one of these innovations. By helping hemophilia facilities reap so many benefits, Cubixx helps them provide the highest-quality care to the patients they serve. ☺

Christopher Flori is vice president of Business Innovation at ASD Healthcare, a subsidiary of AmerisourceBergen Specialty Group, of Frisco, Texas. Reach him at 469-365-7814 or Chris.Flori@asdhealthcare.com.

Inhibitor Insights... from p. 4

MicroHealth offers another way to track bleed data electronically: a cloud-based program (see page 7). It's not exactly an app, because people without smartphones can use it. You set up a customized profile online, and then specify who receives the information you send—this gives you control of your personal health data. The program sends you text messages asking questions such as whether you've infused or had a bleed. The answers you text back go into your profile and can be reported to your healthcare team.

Liz, whose three year-old son has severe hemophilia A with inhibitors, is an enthusiastic user of MicroHealth. "Between ITI and later, prophylaxis, we were doing three infusions a day," Liz explains. "I reached out to the MicroHealth team to help me set it up that way. They actually enhanced MicroHealth to fit my schedule perfectly." Liz set up her profile online, and now just texts MicroHealth if she needs to record anything. "They remind me to log when the next dose is due. That's an awesome feature." She no longer uses paper and pencil for logging. And she is teaching her son how to use the program.

If you do decide to use an app or online program to keep records, be cautious. As with any digital or electronic information-sharing tool, you need to be careful about your personal information. Check the company's privacy policy to see which information it collects and how secure your data will be.²



Liz and James Purvis, with son Benjamin

Mobile apps can help families with inhibitors organize and keep track of every aspect of a treatment plan, especially if several caretakers are involved or if you are on a complicated treatment regimen. Whether you are at school, work, or your HTC, your treatment data is at your fingertips. Having an inhibitor adds to the stress of having hemophilia and complicates daily living, but you may be able to reduce stress by using an appropriate app. ☺

2. For more on privacy, see "Private Parts: Is Your Personal Health Information Exposed?" PEN, Feb. 2012. See www.kelleycom.com/newsletters.

Parenting Moment

Do not confine your children to your own learning, for they were born in another time.

—Chinese proverb

What a computer is to me is the most remarkable tool that we have ever come up with. It's the equivalent of a bicycle for our minds.

—Steve Jobs

Inbox... from p. 2

THANK YOU FOR CONTINUING TO PUBLISH PEN in hard copy. After I read it, it goes into our HTC waiting room. The information is very useful and topical. I congratulate you on your decades of useful volunteerism!

Carol Kasper, MD
Orthopaedic Hospital
CALIFORNIA

I WANT TO PAT YOU ON THE BACK FOR something you showcased in PEN a few years ago ["Another Option for Venous Access in Children with Hemophilia: The Arterio-Venous Fistula," May 2003] that has helped me tremendously. I have factor VII deficiency, and have infused clotting factor for over 13 years, with daily infusions and more as needed for bleeds. At age 61, my veins are becoming more fragile with age, and I'm having difficulty getting a good stick 100 percent of the time.

A surgeon friend of mine who I was consulting about this recommended I have an AV fistula, something I was unfamiliar with. When I mentioned this to my dear friend Janet Brewer from CHES [Comprehensive Health Education Services], she searched her educational files and came up with a 2003 article in PEN, showcasing this procedure. Interestingly, it was pioneered in children with hemophilia by Dr. Leonard Valentino, who heads the Rush University HTC where I received treatment when I lived in Chicago.

This article was extremely interesting and educational for me; the accompanying photos were wonderful, clearly showing what it looks like, and I'm going to bring it along when I meet with the vascular surgeon later this month. This procedure seems to be an ideal option for the aging hemophilia population who infuses regularly. It certainly seems better than the other options, which all involve placing a foreign object, and also are really just temporary solutions. I'm going for my HTC clinic tomorrow at Puget Sound Blood Center, and will show the article to Neil Josephson, MD. Maybe in an upcoming PEN newsletter, the AV fistula procedure could be showcased again, this

time targeting adults? I read PEN cover-to-cover, and am continually awed by the wealth of information in it. Thank you for this wonderful service you provide to the bleeding disorder community!

Barbara Fors
Executive Director/Founder
LadyBugs Foundation

Ed. note: The article is available at www.kelleycom.com/newsletter_archives_2003.html

I HAVE BEEN POSTING A LITTLE "DID YOU know" every day, for hemophilia awareness month [March]. I want to thank you because everything I have learned about hemophilia has in some way come from you.

Michelle Thomas
MISSOURI

THANK YOU FOR YOUR DEDICATION TO THE bleeding disorder community. Your published writing is vital to my patients. We use your books frequently to teach our newly diagnosed hemophilia and von Willebrand disease patients about their disorders and how to live.

Tim Smith, RN
Owner
P3 Compounding & Specialty Pharmacy
ALABAMA

Project SHARE

MY SON, SOHAM SAGAR DHONDE, AGE 21 months, was admitted to Wadia Hospital due to a brain bleed between January 18 and 30, 2012.

He was infused with FEIBA and NovoSeven because he has an inhibitor, and now he is recovered. During the treatment, the Hemophilia Society Mumbai chapter helped me with 2,500 IU of FEIBA and 18 mg of Novo Seven donated from Project SHARE.

I am very thankful to Project SHARE and the Hemophilia Society Mumbai chapter for helping him recover.

Sagar Dhonde
INDIA



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