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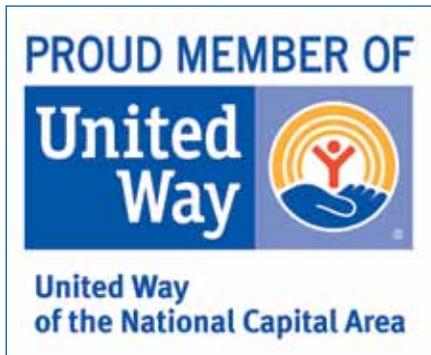
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*A warm welcome awaits you this spring in Louisville, Kentucky – host city of the Hemophilia Federation of America’s 2011 Educational Symposium.*



### RACE AHEAD, DON'T WAIT!

Registration and scholarship information is available on pages 8, 9 & 10 and on the HFA website at [www.hemophiliafed.org](http://www.hemophiliafed.org).

We cordially invite you to join us at Symposium, the community-centered meeting that brings together more than 400 community members, over 100 exhibitors, numerous speakers and volunteers from across the country. This year, HFA will award at least 100 scholarships to attendees. Check out how to apply below!

Symposium unites the community with an educational program designed exclusively for those with bleeding disorders. Moms, dads, spouses, young adults, teens, children, and extended family members share information and participate in community fellowship in a friendly, relaxed and supportive environment.

Educational sessions address the latest in research, physical and mental health care, legislative advocacy, social advocacy and leadership. HFA’s newest area of focus – FitFactor – is designed

to help everyone maintain a healthy lifestyle. This year we will feature sessions with tips and hands-on advice for maintaining good health.

If you choose to arrive early or stay after the conference, Louisville is a host city with a wide range of activities including the Kentucky Derby Museum at Churchill Downs, the Louisville Slugger Museum and the Muhammad Ali Center. You can be sure that HFA Children’s Programs will include visits to some of these exciting venues.

As an added bonus, the kickoff of the annual Kentucky Derby Festival takes place during this year’s Symposium. Our downtown hotel is in the heart of the festival! Symposium attendees who come to our closing event on Saturday night can head outdoors to the largest annual fireworks display in North America, a part of Thunder Weekend. ♦

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## MISSION

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

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## DISCLAIMER

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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## HCV AND ACCESS TO THERAPY

In December 2010, the Food and Drug Administration (FDA) published new draft guidance for industry entitled "Codevelopment of Two or More Unmarketed Investigational Drugs for Use in Combination" to treat Hepatitis C (HCV).

Because the existing developmental and regulatory paradigm focuses primarily on assessment of the effectiveness and safety of a single new investigational drug acting alone, or in combination with an approved drug, FDA published draft guidance to assist sponsors in the codevelopment of two or more unmarketed drugs.

Previous draft FDA guidance was weak in its approach to testing combinations of advanced agents. It indicated interest, but recommended the older, slower model for testing new drugs via addition of single agents to the existing Standard of Care cocktail.

The new draft guidance is intended to assist sponsors in the codevelopment of two or more novel (not previously marketed) drugs to be used in combination to treat a disease or condition. This guidance is distinct from FDA draft guidance of September 2010 that addressed similar topics for HCV only, and provides recommendations and advice on how to address certain scientific and regulatory issues that will arise during codevelopment. It is intended to assist sponsors in the codevelopment of two or more novel (not previously marketed) drugs to be used in combination to treat a disease or condition.

For people with bleeding disorders and HCV greater urgency and focus on rapid drug development is critical. After 25 or more years of HCV viremia, many of us will not survive another decade absent rapid availability of effective, low-side-effect therapy.

When final, this guidance may help provide a framework and path to do something about the serious and deteriorating liver health conditions among our endangered community. Combinations of advanced HCV drugs represent our best hopes for better therapy for HCV within our lifetimes.

In recent weeks, Bristol-Myers Squibb and Pharmasset have announced a Clinical Collaboration Agreement for Proof of Concept Combination Study in Patients Chronically Infected with Hepatitis C. This study is the first cross-company collaboration combining two oral, direct-acting antivirals to evaluate the combination with and without ribavirin in treatment-naïve patients.

For those of you interested, notify your infectious disease/hepatology docs and garner any information. These steps are critical for people with special unmet needs to gain access.

  
Paul Brayshaw



**Helping Hands**<sup>TM</sup>  
Hemophilia Federation of America

## HELPING EACH OTHER: YOU, ME, COMMUNITY

In 2010, HFA was able to directly assist 216 households with emergency financial support via the Helping Hands Program. This amounted to over \$90,000 in aid to keep families in their homes, keep the lights on or other critical needs. Funding for this program has come from a small handful of donors and in the past few years, HFA's Board recognized the urgent nature of our economy and authorized dollars from emergency long-term funds to be used for Helping Hands. While this is an unsustainable way to manage a program, we felt this step was necessary as we try to find alternative sources.

The good news is that reports and the general outlook on the economy seem to be optimistic, indicating slow but positive growth. We hope our community members experience this directly as soon as possible! For Helping Hands, we're expecting a difficult year for our funding. As this article is written, one of our funders has opted out and we have been unable to confirm other support. The many options we've been exploring over the past few years have not panned out.

**DON'T MISS AN  
AFTERNOON  
with the...**

**BLOOD  
SISTERHOOD**  
Hemophilia Federation of America

## Blood Sisterhood Rap Session

Facilitated by Sue Fletcher, PhD & Lew Collins, RNC

Followed by

## "Beyond My Diagnosis"

"Self-Advocating" within the Healthcare System with  
Deborah Brown, MD University of Texas Health Science Center

## DONATE TODAY

Your support will make a big difference in the lives of community members who need our assistance.

You may make a tax-deductible gift in any amount by sending your check to HFA or direct via our website using PayPal.

Please make the check payable to Hemophilia Federation of America, and note in the lower left corner that it is a gift for HH (Helping Hands).

Our mailing address is: HFA, 210 7th St. S.E., Ste 200 B, Washington DC 20003.

If you require additional information, please email us at: [info@hemophiliafed.org](mailto:info@hemophiliafed.org)

Most any of us are simply a job loss away from needing Helping Hands – HFA would like to see the program be around for that need.

This is an appeal. If HFA commits 100% of all Individual and Family Memberships to Helping Hands in 2011, would you sign up? Our distribution for this issue is roughly 10,000. If each reader joins as a \$25 Member, we will fully fund the program... ourselves.

You, Me, Community. We can do this! ♦



JOIN US FOR THIS AND MANY MORE  
PROGRAMS AT SYMPOSIUM

APRIL 14-16, 2011 | MARRIOTT DOWNTOWN  
LOUISVILLE, KY



April 14 - 16, 2011

# Thursday

April 14, 2011

- 1:00 PM - 6:00 PM ..... Registration
- 1:00 PM ..... Exhibitor Set Up
- 1:00 PM - 2:30 PM ..... Nonprofit Best Practices: Facebook, Twitter, LinkedIn and Blogging
- 3:00 PM ..... Young Leaders Kickoff :Today's Technology, Today's Advocacy
- 5:30 PM - 7:00 PM ..... Exhibit Hall Opens to Public

# Friday

April 15, 2011

- 9:00 AM - 12:00 PM ..... Registration
- 9:30 AM - 11:30 AM ..... Exhibit Hours
- 9:00 AM - 11:30 AM ..... Young Leaders Session:  
Today's Technology, Today's Advocacy
- 11:00 AM - 11:45 AM ..... First Time Attendee Reception
- 11:30 AM - 5 :30 PM ..... Children's Programming and Childcare  
(Check-in begins at 11:30am)
- 11:30 AM ..... HFA Teen Programming  
Facilitator: Patrick Torrie
- 12:15 PM - 1:00 PM ..... **Welcome And Recognition Luncheon**
- 1:15 PM - 2:15 PM ..... Keynote Speaker: Clifford C. Kuhn, MD, The  
Laugh Doctor It All Starts With A SMILE!
- 2:30 PM - 3:30 PM ..... Healthcare Reform: The Law Passed,  
Now What?
- 4:00 PM - 5:30 PM ..... **Breakout Sessions: Ready - Set - Go =  
A Call to Take Action**
- 5:30 PM - 7:30 PM ..... Exhibit Hall Open
- 7:30 PM - 10:00 PM ..... Industry Dinner hosted by Baxter
- 8:00 PM - 10:00 PM ..... Blood Brotherhood & Dads Poker  
Tournament

**Breakout 1**  
Be Effective: Using Legislative Web Tools

**Breakout 2**  
Getting Personal: Telling My Story

**Breakout 3**  
Meet the Press: Getting Noticed!

# Saturday

Saturday, April 16, 2011



- 7:00 AM - 9:30 AM ..... Industry Dinner hosted by Bayer
- 9:30 AM - 5:30 PM ..... Childcare & Programming
- 9:30 AM - 10:45 AM ..... Medical Advancement on the Horizon (Panel)  
Topics: Inhibitors, Prophylactic Therapies, New  
Product Developments
- 11:00 AM - 12:00 PM ..... Universal Data Collection...Public Health  
What Changes are in Store for You!
- 12:00 PM - 1:30 PM ..... Exhibit Hall Hours  
(Exhibit Hall Closes at 1:30)
- 12:00 PM ..... **Box Lunch**
- 1:30 PM - 4:30 PM ..... **Community Breakout Sessions**
- 1:30 PM - 2:30 PM ..... Blood Sisterhood: Rap Session
- 1:30 PM - 2:30 PM ..... Dads In Action: "Parents Working Together to  
Make it Happen"...Creating Harmony in Families  
with a Bleeding Disorder (Moms Included)
- 1:30 PM - 2:00 PM ..... Blood Brotherhood: FitFactor, Be Healthy!  
(Partners/Spouses Welcome)
- 2:00 PM - 2:30 PM ..... Blood Brotherhood: HCV and Access to Therapy  
(Partners/Spouses Welcome)
- 2:30 PM - 3:30 PM ..... Blood Sisterhood: Beyond My Diagnosis, "Self-  
Advocating" within the HealthCare System
- 2:30 PM - 3:30 PM ..... Dads in Action: FitFactor...Focusing on Family
- 2:30 PM - 3:30 PM ..... Moms: Rap Session; Partners/Spouses of Blood  
Brothers: Rap Session
- 2:30 PM - 3:30 PM ..... Blood Brotherhood: Just Click on "IT." How to  
connect with your Brothers Whenever, Wherever!
- 3:30 PM - 4:30 PM ..... Women's Health & Wellness Reception
- 3:30 PM - 4:30 PM ..... Dads in Action: Rap Session; Blood  
Brotherhood: Rap Session
- 5:00 PM ..... Remembrance Service
- 6:30 PM - 9:30 PM ..... Kentucky Thunder Fun Fest! A final night event  
filled with food, dancing, entertainment and fun  
for the entire family!

# TRUTH & TRANSPARENCY

By Paul Brayshaw, Matthew Compton, Chad Stevens and Tracy Cleghorn

The Hemophilia Federation of America is proud to introduce a new section of the Dateline Federation newsletter, called Truth and Transparency. This section will seek to address various concerns, as well as define issues which stakeholders, including patients, families, medical providers, industry and academia ask regarding access to care, and healthcare delivery.

As the audience, your input is critical. When issues and scenarios are presented, please engage in the discussion and share your comments for future topics. If you have a question or issue that needs to be discussed, please submit them at any time. HFA ensures the privacy of all communications.

HFA does not offer medical advice. Please direct all treatment questions to medical professional.

## Question

**If I have private insurance, what kind of incentives can I accept?**

## Answer

There is a big difference in having private and government-based insurance coverage, but if you are enrolled in a government program (i.e. Medicare and/or Medicaid) costs of goods, meals or services cannot be greater than \$9.99. For a patient with private insurance the rules are not as clear. Some policies are regulated by federal legislation, depending on the size of an employer, and others are regulated by the state.

Pharmaceutical companies and manufactures are regulated separately and the rules are strict. Unless an educational component is involved in any dinner or meal, manufacturers are unable to provide any remuneration (payment).

For homecare/specialty pharmacy services in the bleeding disorders community, a consumer must assess the quality and value of customer service, and consider the business ethic of the salesperson and the company as a whole. Examples may include expensive meals, sports/entertainment tickets, or anything considered outside of normal and ordinary business practices. 🩸

facebook

### CONNECT WITH HFA ON FACEBOOK

Join the 2,850 people on the HFA Facebook page! Here you will find legislative updates, press releases, HFA program information and much more!

[www.facebook.com/hemophiliated.org](http://www.facebook.com/hemophiliated.org)

### BECOME AN ADVOCATE IN YOUR OWN COMMUNITY.

Stay updated on healthcare reform and other policy issues by connecting with resources at

[www.hemophiliated.org](http://www.hemophiliated.org):

- HFA's Friday Update
- HFA's Legislative Action Center Alerts
- Encourage healthy donors to give blood
- Support clinical trials

## FITNESS FOR ALL AGES! **FITFACTOR**

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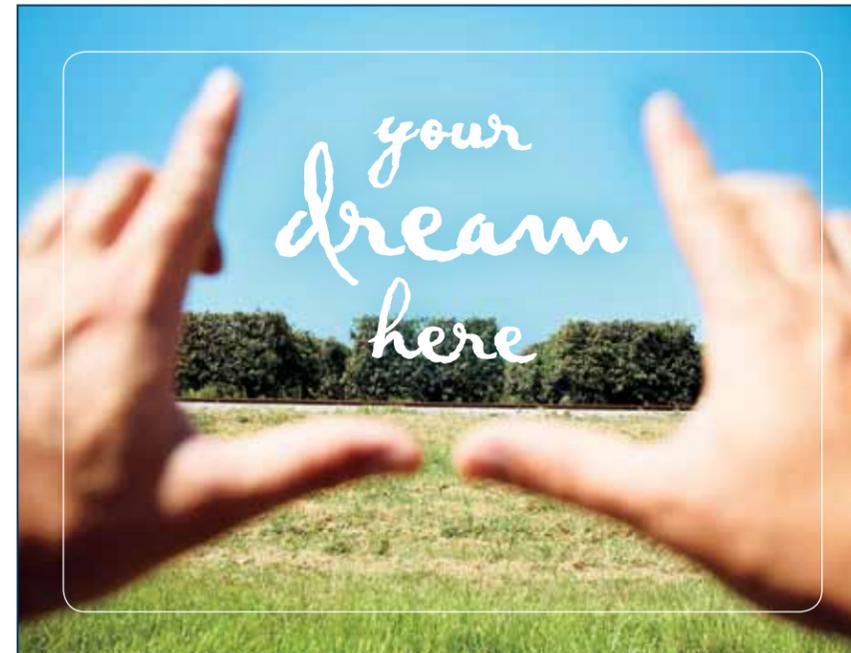


\*Please note that an internet connection is required to receive infusion reminders.

This app is not intended to offer or replace professional medical advice. Speak to your nurse or physician if you have any health concerns. You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch) or call 1-800-FDA-1088.

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**SYMPOSIUM SCHOLARSHIP APPLICATION**

Annual Meeting and Symposium  
Marriott | Downtown - Louisville, KY  
April 15 & 16, 2011

To Register: (Registration Deadline - March 15, 2011.)  
**Completed registration forms and appropriate registration fee must be submitted with this scholarship application and returned to:** Hemophilia Federation of America 210 7th Street SE Ste 200B, Washington, DC 20003  
 Fax: 202.675.6983 Questions call 1.800.230.9797

**First Time Attendees are eligible for Scholarships. Scholarships are limited to funding availability.** HFA's Symposium Committee has requested that you pay the registration fee in order for your scholarship to be processed. If your request for a scholarship is not granted and you are unable to attend, your registration payment will be refunded.

**PLEASE PRINT:**

Name:	Home Phone: ( ) -
Work Phone: ( )	Cell Phone: ( ) -
Address:	City, State Zip
E-mail:	

**Individual**    **Family** (include names of each family member attending and ages of children under 18)

Names of Each Family member attending	Sex	Age	Relation

**PLEASE CIRCLE TYPE OF ASSISTANCE NEEDED: HOTEL / AIRFARE**

Departing City & Airport: 1st Choice \_\_\_\_\_ Second Choice \_\_\_\_\_

Preferred time of departure: \_\_\_\_\_

Are you or your spouse employed by a Homecare Company or Manufacturer  Yes    No

If yes, please identify Company \_\_\_\_\_

Have you received a previous HFA Symposium scholarship  Yes    No

**Relationship to Bleeding Disorder:**  Factor VIII    Factor IX    vonWillebrand's    Other \_\_\_\_\_  
 Parent    Child    Sibling    Spouse    Other \_\_\_\_\_

How did you find out about the HFA Educational Symposium?  
 \_\_\_\_\_  
 \_\_\_\_\_

HFA use only: Date Received \_\_\_\_\_ Referred By: \_\_\_\_\_ Date of Notification: \_\_\_\_\_

**HFA 2011 PATRONS**

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|---|--|

HFA gratefully acknowledges the generosity of all valued donors on the website at [www.hemophiliafed.org](http://www.hemophiliafed.org).

JOIN US FOR THIS AND MANY MORE PROGRAMS AT SYMPOSIUM  
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**"HCV and Access to Therapy"**  
 With Mark Antell and Paul Brayshaw

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 How to Connect with Your Brothers  
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The Institute of Medicine (IOM) is doing a study that will make recommendations on the criteria and methods for determining the essential benefits in health plans

that will be offered in health insurance exchanges starting in 2014. As you may recall, healthcare reform mandated that by 2014 adults will need to purchase health insurance or face a tax penalty. To help individuals decide what type of plan to purchase, health insurance exchanges will be set up by states to provide a one point "stop and shop" for the public. The exchange is technically not an actual place but will more likely be a virtual marketplace where individuals can go online and browse insurance offerings based on personal criteria they identify such as, age, health status, and other personal characteristics. The U.S. Department of Health and Human Services (HHS) will most likely be issuing regulations regarding how states should set up this process by the fall. In the meantime they have asked the IOM to do a study on how the essential benefits in these plan offerings should be designed. Essential benefits refer to what the plans will actual offer in coverage, as a baseline for services, treatments, etc. It is a starting point for health insurance plans; they will be mandated by law to offer these "basic" or "essential benefits" to the public for purchase. The IOM will also be providing recommendations on how these benefits should be updated over time, for example to allow for the inclusion of new treatments. The IOM will also review how insurers determine covered benefits and medical necessity. The outcome of this study will be a published report released in September which will lay out the criteria

## DETERMINING ESSENTIAL BENEFITS IN HEALTH CARE REFORM

By Eboni Morris, HFA Policy Analyst

the HHS should use in crafting federal regulations on essential health benefits offered in the health insurance exchanges.

HFA submitted written comments to the initial survey conducted by the IOM in December, where several areas of concern were identified:

- Essential benefit packages should be designed to encourage patient access and not impede patients from obtaining needed treatments and specialized care. Health plans should look to medical literature and treatment guidelines recommended by medical and patient organization to determine standards of care for patients with rare and chronic conditions.
- The essential benefit package should allow patients access to needed specialists and allow the physician to formulate the best treatment regime for patients at the appropriate site of care whether in the hospital, outpatient clinic, office of the physician, hemophilia treatment center (HTC) or the home setting.
- The essential benefits package should always include a process to appeal a claim denial. That process should provide assurance that the insurer has an obligation to first confer with the patient's physician to discuss a possible denial and the grounds for rendering such a decision.
- HFA opposes any additional limits on specific or total benefits in the packages given the statutory restrictions on lifetime and annual benefit limits already authorized in healthcare reform. HFA recommends prohibiting the implementation treatment caps of any kind by providers either by cost or in limits on treatment that has been approved by the United States Food and Drug Administration (FDA).
- State mandates have been invaluable to rare, chronic and high cost disease groups, who might otherwise be excluded from private insurance

coverage. Any decision to phase out a given state mandate, where the national program provides similar protection, should be made cognizant of the possible disruption in coverage that might ensue for these particularly vulnerable groups.

- As advances in medical evidence or scientific advancement are being uncovered and approved through the FDA, as well as peer reviewed medical journals stating the improved/decreased health outcome, HHS must put in place expeditious pathways for the inclusion of new therapies and treatments in the essential benefits package when these new products or new information become available.

IOM has entered the next phase of this process and will be holding a series of public meetings to hear from various stakeholders regarding essential benefits. The first meeting took place during the week of January 12-14, 2011 and covered numerous topics within essential health benefits including: the original legislative intent of health care reform regarding essential health benefits, stakeholder recommendations for defining health insurance packages, issues regarding medical necessity, how insurers determine benefit design and coverage and various perspectives from patients and health advocacy groups.

Some common themes emerged from the presentations:

- Insurers argue that essential benefits should not be heavily prescribed through regulation to allow for the market to determine which benefits provide the

best coverage options. They also cautioned against adopting state mandates because of the tens of thousands already in existence across the country. They argue that adopting a multitude of mandates on the national level will bring a dramatic rise in health insurance premiums.

- Patient and health advocacy groups argued that patients with chronic disease need access to treatment and providers of their choice. Essential benefits must be designed so that this access is not denied. They urged the panel to ensure that the benefits reflect the diverse healthcare needs of the U.S. population and are based on appropriate standards of care and practice. According to the advocacy groups, the inclusions of some state mandates are necessary to maintain comprehensive care for those with complex health needs.

HFA staff will be attending these public meetings in Washington D.C. and will be monitoring how the process unfolds. Be sure to monitor healthcare reform action in your state. States will be holding public hearings and introducing and passing legislation to set up various aspects of health reform. ♦

### RESOURCES TO KEEP YOU INFORMED

- [www.healthcare.gov](http://www.healthcare.gov)
- [www.kff.org](http://www.kff.org)
- <http://www.iom.edu/Activities/HealthServices/EssentialHealthBenefits.aspx>
- <http://www.ncsl.org/default.aspx?tabid=20231>



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John Beed  
DPH

*We only have one mission: We would like for you to be able to look back and say, "My life with hemophilia is better today than it was before we met."*

John and Carol Reed

### VISIT THE HFA WEBSITE TODAY!

Were you one of the 29,000 visits to the HFA website in 2010? If not, check it out! Our website is updated weekly with new articles, upcoming webinars and much more!

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Just 3 easy steps to enroll

1. Print a product request form at [www.FactorPlusprogram.com](http://www.FactorPlusprogram.com) or call 1-866-767-4883.
2. Share the form with your doctor and discuss whether Helixate FS is right for you or your child.
3. Ask your doctor to complete the form and send it in for processing.

For more information and to get started, visit [www.FactorPlusprogram.com](http://www.FactorPlusprogram.com).

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.

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CALLING DADS AND MOMS!



Join us for

**“Parents Working Together to Make it Happen...”**

*Creating Harmony in Families with a Bleeding Disorder  
with **Dr. Dave Robinson***

*Dr. Robinson has a PhD in marriage and family therapy. He is a licensed and practicing marriage and family therapist and an associate professor at the University of Nebraska Medical Center. He and his wife Jamie have five children (three boys and two girls) ages 17 to 5. The oldest and youngest both have moderate factor IX hemophilia*

Followed by

**Rap Sessions for Dads**

*Co-facilitated by Dr. Dave Robinson and Mark Zatyрка*

**and for Moms**

*Facilitated by Nikita Murry, RN*

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