

# The Clotting Connection

*A Newsletter for Families with Bleeding and Clotting Disorders*

December 2017  
Volume 7, Issue 12



University of Colorado  
Anschutz Medical Campus  
Hemophilia and Thrombosis Center

Affiliated with  
Children's Hospital Colorado  
and University of Colorado Hospital

## HTC PHARMACY ACHIEVES FULL URAC ACCREDITATION



The University of Colorado HTC Pharmacy has been providing customized patient centered care since 1995. We are pleased to announce that our pharmacy has earned URAC accreditation in Specialty Pharmacy. URAC is the independent leader in promoting healthcare quality through accreditation, certification and measurement. By achieving this status, the HTC Pharmacy has demonstrated a comprehensive commitment to quality care, improved processes, and better patient outcomes.

URAC is the leading non-profit accrediting organization for specialty pharmacies. They have stringent requirements including evidence-based measures and standards for the pharmacy.

"It is necessary for specialty pharmacies to provide a higher level of treatment for patients so desired outcomes are achieved. The University of Colorado HTC Pharmacy shows a dedication to patient education and safety through the recognition of quality it received with URAC's independent accreditation," said URAC President and CEO Kylanne Green. "With URAC accreditation, people know that the University of Colorado HTC Pharmacy strives to adhere to industry best practices."

What does this mean to you, our patients? In response to the ever changing healthcare climate and changes in the specialty pharmacy field, our Pharmacy team here at the HTC felt it was vital to be up to date and working to serve patients in a way that adheres to industry standards. The HTC Pharmacy will continue to offer the same services they always have but, in addition, patients will have the benefit of being enrolled in the pharmacy's Patient Management Program.

Our Patient Management Program offers patients:

- Individualized patient care planning for upcoming procedures and surgeries
- Monthly refill reminder calls and coordination with your healthcare team to monitor and support therapy adherence
- Access to HTC pharmacists 24/7
- Better and more frequent communication with your pharmacy team in the form of handouts, surveys, and patient education
- Annual patient assessments to monitor how your bleeding disorder is managed, areas for additional education, and the effects of your bleeding disorder on your quality of life.
- New and more sophisticated packaging and temperature monitoring for shipping supplies and medication to patients.

The accreditation process took more than a year to complete, requiring regular updates and detailed compliance to stringent standards. The process allowed us to evaluate our systems and find ways to improve and bring the best care to patients.

The HTC Pharmacy will pursue a second accreditation in 2018 ensuring quality standards for our patients as we move into the future. We congratulate the pharmacy's efforts in achieving the URAC accreditation, and thank all of our staff who participated in this accomplishment.



One of our research staff, Molly Brown, helps at our Pediatric Stroke Support Group Holiday Party. More pictures inside.

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Find us on Facebook, Twitter, and our website for frequent updates on news and events.



Go to [facebook.com/ColoradoHTC](https://facebook.com/ColoradoHTC)



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Website: Go to [medschool.ucdenver.edu/htc](https://medschool.ucdenver.edu/htc)



Email:

[HTC.Newsletter@ucdenver.edu](mailto:HTC.Newsletter@ucdenver.edu)

## HOLIDAY CLOSURES & SHIPPING DEADLINES



The HTC Clinic, Pharmacy and Administrative Offices will be closed for two days at Christmas, New Year's day and Martin Luther King Jr. Day. If you have medical concerns or will need to order factor before any of the upcoming holidays, please be sure to contact us as soon as possible.

### Our Clinic, Pharmacy and Offices are closed on the following dates:

Mon, & Tues, Dec 25-26, 2017 **Christmas Holiday**  
 Mon, Jan 1, 2018 **New Year's Day**  
 Mon, Jan 15, 2018 **MLK Day**

During these times if you have an urgent medical issue:

**Adult Patients: 720-848-0000 to page the Hematology/Oncology Fellow on call, or go to the University Hospital Emergency Room.**

**Pediatric Patients: 303-785-3335 or toll free at 1-800-536-5105 to page the Hematology/Oncology Fellow on call who will direct you where to go.**

**To obtain emergency factor from our HTC Pharmacy, please contact the pharmacist on call at: 303-724-0168 or toll free at 1-888-724-7427.**

Winter weather conditions can be unpredictable. Please plan ahead to ensure you have enough factor on hand in the event your factor order is delayed due to inclement weather or FedEx holiday closures. Our deadlines for shipping before holidays are as follows:

**Last date to ship:**  
**Before Christmas** **Thurs, Dec 21, 2017**  
**Before New Years** **Thurs, Dec 28, 2017**  
**Before MLK Day** **Thurs, Jan 11, 2018**

Our pharmacy appreciates your help in calling in any orders sooner than these dates if possible.

Thank you for planning ahead.

## PARENTS EMPOWERING PARENTS

Simply put, parenting is hard work. Yes, it is one of the most rewarding and wonderful experiences you will ever have, but it is also exhausting, frustrating, and time consuming. And it can be even more challenging when you are raising a child with a chronic medical condition, like a bleeding disorder. That is why the Parents Empowering Parents (PEP) program was created.

Parents Empowering Parents (PEP) was organized in 1995, primarily by a social worker in Michigan and in collaboration with Bayer. Over the years, many other professionals in the hemophilia community have worked to make PEP the program it is today. It is a free program offered at various treatment centers across the country. PEP is a weekend-long workshop co-facilitated by an HTC social worker, nurse, and PEP trained parents from the hemophilia community.

The primary purpose of PEP is to offer support and resources to parents of children with a bleeding disorder in a safe and nonjudgmental environment. It provides an opportunity for parents to connect with other parents and share ideas and experiences that will help you better support and care for your child. As a parent of a child with a bleeding disorder, only you can speak to the challenges you have faced, and who better to learn from than other parents facing similar challenges.

We currently do not have the next PEP scheduled, but if you are interested, please contact Audra LeBlanc at 303-724-6163 or at [audra.leblanc@ucdenver.edu](mailto:audra.leblanc@ucdenver.edu) and she will work with you to coordinate a PEP that fits into your schedule.



## DR. CHRIS NG WINS AWARD

The National Hemophilia Foundation (NHF) announced this month that Dr. Christopher Ng, Assistant Professor of Pediatrics here at the University of Colorado, is the 2017 recipient of the 2017 NHF/Novo Nordisk Career Development Award (CDA). This is a research award that will provide \$70,000 a year for up to three years. Dr. Ng will be using the funding to study von Willebrand Factor regulation in blood outgrowth endothelial cells. He hopes that his research will help shed light on the molecular understanding of VWD, advance other areas of investigation, and lead to better diagnostic and prediction methods for bleeding in VWD.

Some of you may have met Dr. Ng as he treats patients in our HTC clinic or works with our lab. Congratulations to Dr. Ng as he moves forward with research to further provide support and insight into the bleeding disorders many of our patients are managing daily. For an in depth article on this award, please go to [hemophilia.org/Newsroom](http://hemophilia.org/Newsroom) and look under the Community News section.



# STROKE SUPPORT GROUP HOLIDAY PARTY

Our Pediatric Stroke Parent Support Group had a fun Holiday Party earlier this month. Santa and his elves were there to help the kids decorate cookies and make cards. Much fun was had by all. Thank you to all who were able to come support and participate in this fun annual event! Our next support group meeting will be January 9, 2018. Please see our webpage for updated information: [pedsstrokesupport.ucdenver.edu](http://pedsstrokesupport.ucdenver.edu). Happy Holidays!



## RECENT HEADLINES

These are a few of the headlines that we've recently featured on our Newsroom page or on Facebook.

### **BioMarin Shares New Data on Gene Therapy for Hemophilia A**

### **Gene Therapy Shows Promise for Hemophilia B**

### **Shire to Develop New Way to Administer Hemophilia Medications**

### **2017 NHF/Novo Nordisk Career Development Award goes to Dr. Chris Ng**

### **Startup Could Bring Back Vioxx for Hemophilia Patients**

We maintain a Newsroom page at our website with a list of the news we feel may be of interest to our patients and families. To see more go to: [www.medschool.ucdenver.edu/htc](http://www.medschool.ucdenver.edu/htc) then find the **RESOURCES** tab, and go to the **NEWSROOM** page. Find other stories at our Facebook page at [www.facebook.com/ColoradoHTC/](http://www.facebook.com/ColoradoHTC/)

## UPCOMING EVENTS

### **Mark Your Calendars/Save the Date:**

**Dec 25-26:** Clinic, Pharmacy & Admin closed for Christmas Holiday

**Jan 1:** Clinic, Pharmacy & Admin closed for New Year's Day

**Jan 9:** Pediatric Stroke Parent Support Group Meeting

**Jan 13:** Backpacks + Bleeders Hike

**Jan 15:** Clinic, Pharmacy & Admin closed for Martin Luther King Jr. Day

**Feb 6:** Self-infusion Clinic

**Feb 9:** Outreach Clinic-Colorado Springs

**Feb 19:** Clinic, Pharmacy & Admin closed for Presidents' Day

**Feb 23-25:** RMHBDA Education Weekend & Annual Meeting

**June 16-21:** Camp for Kids with Neurologic Disorders at Roundup River Ranch

**July 15-20:** Mile High Summer Camp

See more at our Events Page on our website: [www.medschool.ucdenver.edu/htc](http://www.medschool.ucdenver.edu/htc) find **RESOURCES** tab, go to **EVENTS**

### **Hemophilia & Thrombosis Center**

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or toll free at 888-297-0724  
Pharmacy Main: 303-724-0168  
or toll free at 888-724-7427

Web page:  
<http://medschool.ucdenver.edu/htc>

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