

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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University of Colorado
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Hemophilia and Thrombosis Center

Affiliated with
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The Director's Corner



Dear Family and Friends,

Welcome to 2016 from the HTC.

We would like to welcome you to the New Year with a host of plans to serve you better. I and the rest of the staff have spoken to many of you about how to improve your clinic experience and we have heard you. Continuity and being known are important themes. We have addressed this in many ways. We have staff teams for each day of the week. We are trying to improve our computer scheduling system by entering the team members that you likely need to see on our end.

We are improving our internal communication so that the scheduler knows who is in clinic on any given day so that you aren't disappointed that a person you expected to see is out of the office. You can help by specifically telling the scheduler which team members you would like to see and Marianna and Bev will accommodate you. Mondays and Thursdays will primarily be for bleeding and clotting in children, Wednesdays are for adults, and Tuesdays and some Fridays are for stroke. Urgent visits can be handled for any age on any day.

We have also reconfigured our teams. Each team has had a nurse, social worker and physical therapist in addition to one or more physicians. We have added a nurse practitioner, Susan Harvey, to the HTC. Now, with Susan along with Elizabeth Gibson, a physician assistant, each team will have one of these two to provide continuity, keeping together the current health needs and treatment plan for each patient, in addition to serving as a care provider. Susan and Elizabeth will ensure that the plan decided upon in clinic gets executed.

We are also embarking on a project to improve our communications and functions as a team. Our Maternal and Child Health Bureau hemophilia grant partners have identified this as an issue of special importance nationally. Our hemophilia region will send a representative to a training program centered at the Dartmouth Institute for Health Policy and Clinical Practice in New Hampshire, and in February, training will begin for a core team at our clinic lead by Dr. Mike Wang. The goal of the training is to develop a cadre of well-trained health care providers on a single team who can affect positive changes to promote health, improve care delivery and communication, and prevent error. While team leadership will affect how we approach every interaction, a focus of special importance is the transition of young individuals from parental to self-care and autonomy.

We look forward to another great year serving you and hope you will remain active participants in our dialog.

Sincerely yours,

Dr. Marilyn Manco-Johnson



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



Go to facebook.com/ColoradoHTC



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Website: Go to medschool.ucdenver.edu/htc



Email: HTC.Newsletter@ucdenver.edu

GOT GOALS?



It's the time of year when goals are made and a fresh start beckons. If you've ever made a list of New

Year's resolutions in January and tucked it away in a drawer by February, you know it isn't always that easy to reach those goals. Don't despair. According to research at the University of Scranton in Pennsylvania, "between 40-46 percent of people manage to keep their New Year's resolutions at six months... You are ten times more likely to change by making a New Year's resolution compared to non-resolvers with the identical goals and comparable motivation to change." * Setting those goals gives you a better chance!

What can you do to keep up the effort to make positive changes in 2016? Below are a few ideas and tips to achieving those goals.

Keep it Short & Write Them Down

One of the most recommended methods to reach your resolutions is the easiest. Take the time to think about what you want to accomplish, limit your goals to just a few, and write them down. Too many goals can be overwhelming; if you never write them down, it's far more likely you'll forget about them. Take the first step, ponder a few achievable goals, and simply write them down.

Visualize

Writing resolutions down doesn't do much good if you keep them out of sight. Whether you print out pictures of your desired goal, paste the list on your fridge and mirror, or have printed quotes to remind you, parking that goal in front of your face will be more

effective than hiding it in a notebook somewhere. Put them on your phone and have calendar reminders pop up on a regular basis to keep on track.

Share

As awkward as it may seem, sharing what your goals are can help motivate you to move forward. Posting on social media, talking to friends, family, or co-workers about your goal, and teaming up with someone can be big motivators



and those friends can push you to be better. Healthy competition can motivate you to go further than you

were planning, and help you achieve goals quicker. Something as simple as a daily challenge or regular texts to a friend can do the trick.

Start Now, and Re-start Tomorrow

Just because you have a grand goal that you've already blown in the first week or two doesn't mean you should give up. Set a time every week or month when you can review what is slowing your progress and plan to adjust as you go. Look at it as a monthly goal, or a weekly one, or even a daily goal to keep starting anew every day and a year-long resolution won't seem so unachievable.

Have a System/Set a Schedule

No matter what your goals are, it can be helpful if you have a detailed system to help keep you on track. Break up large goals into smaller, achievable steps that you can check off through the year, month by month and day by day. There are apps for every smartphone with settings to remind

you, and there are many ways to use automation to help achieve goals. Ask yourself what smaller steps you need to take to reach that goal. Write those small steps down and schedule when and how you will achieve them. Small steps are still steps in the right direction.

Reward Yourself

Sure, achieving a goal is a reward in itself, but having a small physical reward is a good motivator. When penning your resolutions, think about what kind of healthy and reasonable reward you would enjoy as a victory prize. Keeping a picture of that reward or setting a date to redeem it can help inspire success.

Attitude Adjustment

Having a good attitude is a big part of success. Think about the motivations behind

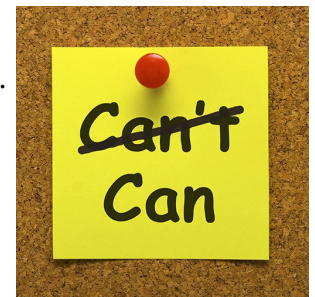
your resolutions. Do you really want this or is it something others want?

Realize you may have hard days and plan ahead; prepare small things to keep your attitude positive and motivate you when things aren't working. Having visual reminders-journaling, finding the right soundtrack for your goal, or taking time for meditation-can help you face the challenges with an attitude that will allow you to keep going and keep trying.

Good luck with those goals, and may the year ahead be full of accomplishment.

We have links to several online articles about this topic on our digital version available at our website: www.medschool.ucdenver.edu/htc go to RESOURCES & find the NEWSLETTER tab.

*blog.heart.org/make-new-years-resolutions-stick/



HTC SPOTLIGHT: TYLER BUCKNER, MD, MSC



Recently the HTC's Dr. Tyler Buckner was the recipient of the American Thrombosis & Hemostasis Network (ATHN) Dream Award. This research grant is offered through the collaboration of the Hemostasis & Thrombosis Research Society (HTRS) and ATHN and was presented at their

annual Summit held in Chicago this past November. This award provides a \$50,000 grant to further his research over the coming year.

Tyler is an Assistant Professor and one of the doctors on staff in our clinic here at the HTC. He regularly sees patients in our clinic and on the wards. He has been working at the HTC since January 2015 and enjoys spending quality time with our patients. He attended Rhodes College in Memphis, Tennessee, The University of North Carolina School of Medicine in Chapel Hill, North Carolina, and the University of North Carolina, Gillings School of Global Public Health in Chapel Hill.

Tyler divides his time in clinic with research at our center. The grant he received from ATHN/HTRS will support a

project that will use the ATHN Core Dataset to investigate the utilization patterns of orthopedic surgical procedures to treat joint disease in individuals with hemophilia. The long-term goal of this work is to optimize the use of these procedures so that they provide as much benefit to our patients as possible.

In addition, Tyler has been working on a study evaluating the impact of hip and knee replacement on pain, physical function, and quality of life in men with hemophilia. He is also developing plans for investigations of how to improve pain assessment in hemophilia.

In his spare time, Tyler enjoys reading; especially fiction, biographies and historical based works. He recently told us, "One of the books I'm reading right now is *The Last Lion*, by William Manchester. It's a biography of Winston Churchill, who I'm learning was a truly fascinating and extraordinary person." He also enjoys woodworking as a hobby, working to improve his skills by creating furniture and other items.

Our staff loves working with Tyler and he enjoys the energetic and fun environment created by our clinic nurses and research staff. He first became interested in working with patients with hemophilia and blood disorders by learning of patients and the stories of the challenges they face on a daily basis. He gets great satisfaction from helping patients achieve their goals and dreams and spends much of his time in clinic finding ways for patients to improve their daily lives.

RETURN YOUR PACKING SLIPS

When you receive factor or other medications from our HTC Pharmacy, please be sure to pay attention to the paperwork included in the packaging. There will be two copies of a packing list included. **One copy is to keep for your records and a second copy is stamped in red ink for you to sign, date, and return.** A self-addressed and stamped envelope is provided to make returning the delivery receipt easy and painless.

Failure to return the signed packing list verifying that you received the medications could result in a delay in receiving your next factor order or possibly being held financially responsible for the order.

Please contact us if you have questions. Our main pharmacy line is 303-724-0168 or toll free at 888-724-7427 and our email is: hemophilia@ucdenver.edu.

Complying with healthcare regulations is a partnership between you and your pharmacy. Thanks for doing your part to help us be in compliance!

SIGN UP FOR THE NEWSLETTER TODAY!

To save resources and produce less waste, we are sending and sharing our monthly newsletters mostly digitally. (We have paper copies in the clinic and you can request we mail one to you.)

If you sign up online you will be the first to get it in your email box; even before we share on social media or finish printing the paper copies. We promise, we will never share your email info, we just want to keep in touch. Sign up online by going to our website and filling out a short form. Go to:

www.medschool.ucdenver.edu/htc and click on the **RESOURCES** tab for the **NEWSLETTER** page. Then click on the link to sign up! It's super easy!

If you have feedback, or would like to suggest a story idea or topic, please send us a note at HTC.Newsletter@ucdenver.edu or give us a call at 303-724-2309

RECENT HEADLINES

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

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 head to: www.medschool.ucdenver.edu/htc then find the **RESOURCES** tab, and go to the **NEWSROOM** tab.

Drugmaker Shire to Purchase Baxalta for \$32 B

Gilead Snags Priority Review for Pangenotype Hep C Combo Treatment

Octapharma's NUWIQ Available in the US to Treat Hemophilia A

Sernova Awarded Grant to Fund Development of Cell-Based Treatment for Hemophilia A

SIPPET Study Results Presented at ASH

Arsia & Biogen Unite to Develop Subcutaneous Delivery for Hemophilia Medications

UPCOMING EVENTS

Feb 9: Pediatric Stroke Parent Support Group Meeting at Brain Injury Alliance of Colorado

Feb 11: NHF Colorado Scholarship Night

Feb 15: Clinic & Admin offices closed for Presidents' Day

Feb 19-21: RMHBDA Education Weekend

March is Hemophilia Awareness Month

Apr 8-10: NHF Colorado Education Dayz

Apr 17: World Hemophilia Day

June 6-8: Outreach Clinic– Billings, MT

Jul 8-10: Mile High Camp Leadership Pre-Retreat

Jul 10-15: Mile High Summer Camp-Rocky Mountain Village

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

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Web page:

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

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