

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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University of Colorado
Anschutz Medical Campus
Hemophilia and Thrombosis Center

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

DIRECTOR'S CORNER



All of us at the HTC want to welcome you to a busy and exciting year. A lot has been happening here on the Anschutz campus and we want to update the Community.

We have been in the UPI Building for five years. The substance of our evolution is all about people and relationships. As you may know, Judy Primeaux retired from the pharmacy and finances last March, and Brenda Riske retired from regional and national coordination in May. We were very sad to see them leave and wish them the greatest health and fulfillment in retirement. However, all changes, even unwanted ones, come with opportunities and many creative people in the HTC came forward to fill in needed roles.

Our Director, Dr. Marilyn Manco-Johnson.

Donna Oscepinski became our program coordinator and is now our go-to person for personnel, policies and many other issues. Rae Gerold-Smith has kept the facilities going without a hitch; she has an additional role supplying us with fresh organic eggs. With the help of Donna and Rae, we were able to integrate many new staff with comfortable homes in our center; they have eased many of the stresses of transition.

Our programs have flourished. We now boast six pediatric hematologists, two adult hematologists, two child stroke neurologists, one adult stroke neurologist, four pharmacists, and two gynecologists. Our scheduled clinics are now running four to five days a week and typically at capacity. Dr. Tyler Buckner is building his career on the measurement and amelioration of pain in hemophilia and has already contributed important clinical research findings nationally. Dr. Beth Warren is tackling the sticky problem of break-through bleeding on prophylaxis and is developing a prospective study to achieve personalized and effective infusion schedules for persons with hemophilia. Dr. Mike Wang is leading clinical trials for many novel factor VIII, factor IX and non-factor products. He is hopeful that he will be able to offer exciting trials for a genuinely extended half-life factor VIII in the next few years. Dr. Jennifer Armstrong has developed the largest organized neonatal stroke and brain injury program in the country and Dr. Tim Bernard is expanding the child and young adult stroke program with support from the American Heart Association. All of our wonderful clinical research would not be possible without the excellent clinical research assistants who get the trials done. We are now up to 7 Clinical Research Coordinators and have also added a statistician, Dianne Thornhill, in addition to Rick Shearer our database manager, and Kevin Anthony in IT.

Our clinical team is coordinated and greatly enriched by the talents and efforts of Elizabeth Gibson and Susan Harvey who provide unparalleled clinic care and care coordination to persons with bleeding and clotting disorders. This year we were privileged to add Christine Mashburn as nursing manager. Ms. Mashburn is working with Dr. Wang to improve the quality of our care, to develop continuity teams, and to enhance our communication skills, all to improve patient services. Our nurses, Nancy Spomer, Kim Hurdstrom and Amber Casey, and medical assistant Amy Cowell, provide the patient education and empowerment that our program is built upon. Our front desk team, Bev Aron and Rose Drake, have worked hard to revamp

[Continued on page 3]



INSIDE THIS ISSUE

- Director's Corner- Dr. Marilyn Manco-Johnson updates the State of the HTC
- Plan a Positive Outlook this Year
- News
- Events

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



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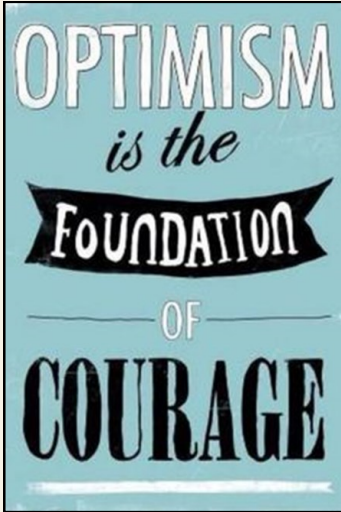


Website: Go to medschool.ucdenver.edu/htc



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PLANNING A POSITIVE NEW YEAR



January brings goal setting, getting a fresh start, and planning a new year. But like most of us, sometimes those goals fall short, or things just don't go as planned. Circumstances beyond our control can leave us feeling blue and disappointed, and it may seem as if nothing is going our way. Yet a bad day, or even a bad year doesn't determine our attitudes, it is a choice we make.

While it won't fix a chronic medical condition such as a bleeding disorder, having a good attitude won't make it worse, and studies show a sunny outlook might actually help your health. Research shows substantial evidence that those who take on life's challenges with positive thinking and a more optimistic view can improve their health and often can contribute to healing and better quality of life.

If things look down and you don't know where to start, we've found a few helpful ideas to keep a positive view.

Smile

We've all been there: you're in a bad mood and someone flashes you a smile, and suddenly you are smiling back. Smiling is proven to lift our mood and even provide endorphins that make you physically feel better. Making an effort to smile, even when you don't feel like it has positive side effects. Smiling can change a gloomy outlook to a sunny one and can alter someone else's day too. If you feel your attitude is lacking, start small and smile at someone. Watch what responses you get. It's a natural human response to smile back, and you get the positivity as well as sharing it.



Be Grateful

Find ways to show gratitude every day and every day you'll be grateful. Being grateful and taking the time to reflect and express thanks is directly linked to positive attitudes. It is easy to look for bad things or to gripe, but often we have many positive things we might be overlooking. If you find you are having trouble switching your attitude, set aside time to regularly write down things that you appreciate. Sending thank you notes, or simply making a list of good things can help focus the mind on the positive things.

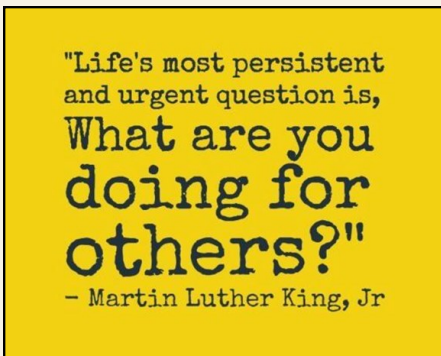


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Surround Yourself with Positive People

If your closest circle is constantly looking for the negative, find ways to touch base with those who see the sunnier side. Constant negativity can be grating, and finding others who can see the good can help lift your attitude. Find opportunities to have conversations with optimistic people, especially ones who bring a smile to your face. And pay it forward; be the one who lifts the mood of those stuck in negativity and help them see the good.

Help Others



When we get stuck in a rut or feel bad about ourselves, reaching out and lending a hand to someone can improve your mood and outlook. When you give of your time, energy, experience or kindness not only does it help the person or group you are serving, you get the benefit of feeling good too. People who regularly give service to others tend to have a better attitude and outlook. Those with bleeding disorders have unique experiences and those can uplift and help those in similar circumstances. If you don't know where to start there are many resources available.

[Continued on page 3]

[Continued from page 1]

the scheduling process to be more user friendly. Our two physical therapists, Sharon Funk and Laura Fox, are the envy of hemophilia patients and programs nationally; we are in the process of adding a third position to continue the same high level of service as our population grows and to prepare for smooth continuity into the future.

Paul Limberis, our Pharmacy Director, assumed responsibility for the hemophilia 340B program. As part of this role, Paul is leading us in pharmacy accreditation which will allow us to continue to contract with as many insurance companies as possible to support patient access to our services and programs. We are looking into programs in nutrition and fitness that will further elevate the health of our bleeding and clotting community. The support team of Lynn Magnuson and Candice Murchison advocate for insurance approval and professional accounting. We couldn't function without them. This year we hope to add a managed care marketer to help keep our pharmacy on your insurance plans.

All of this gives me the enviable job of being able to survey the great work and progress of those all around me. I feel particularly blessed at this stage of my career to see patients I first met as babies and young boys now rising as pillars of our community. Dr. Jasper Hillhouse, who gives back to the community as a pediatrician, volunteered his medical expertise at summer camp. I had the privilege of hearing Roman Samuels perform his original music with voice and guitar and he is a wonderful singer-songwriter who will rise rapidly in the arts; be sure to hear him perform. Lewis Parker continues to develop software solutions to aid our outcome research and quality improvement in hemophilia nationally. Sean Jeffrey joined the NHF Colorado Chapter as a program coordinator bringing skills he honed during his work with student life at the University of Montana. Greg Mah is helping us enter the 21st century with record storage and retrieval. Chris Bombardier has climbed 5 of the 7 highest continental peaks and is heading for Everest in March! There are too many of you to mention individually but I am thrilled every day to see who you are becoming. Many of you are compassionate, caring parents, siblings, teachers and coaches helping to raise the next generation with optimism and courage. I am in awe of all of you.

You are the reason we are here and our goals are based on your visions, aspirations and dreams. We want to dialog about the exciting present and future of bleeding and clotting disorders and focus in the direction that best supports your needs. We hope to see as many of you as possible in clinic, at outreach, at camp, Education Dayz, family retreats and on the hiking trails. Have a wonderful 2017 and tell us about it!

Kind regards,

Marilyn J. Marco-Johnson MD

[Continued from page 2]

**Do what you do
so well that they
will want to see
it again and bring
their friends.**
(Walt Disney)
POSITIVEMOTIVATION.net

An easy way is to serve is to check with your local NHF Chapter, a local school, your religious organization, or other local support groups and simply offer to help. There is always a need to be found.

**Find Things You
Enjoy and Do
Them**

It sounds simple, but whether it's biking, playing music, dancing, hiking, or taking pictures, find things that bring you joy and make time for them. Many of us get caught up in the mundane things of life, and forget to have fun. Life is busy, but make an appointment with yourself for whatever it is you enjoy and take that time to do it. The results can lift your mood and bring a positive outlook on life, and even improve your health.

While these are just a few ideas, we know some of our patients are experts. We at the HTC are lucky to know many of our patients who, despite significant medical challenges are able to look at things in a positive light and do many of these suggestions every day. We are inspired by our patients, and are excited to see them achieve! If you would like to share how you or a family member has overcome challenges, and learned to face life in a positive way, let us know!

We love to highlight our patients here in our newsletter and allow their achievements to lift others to see that they can reach their dreams too.

Send us a note at **HTC.Newsletter@ucdenver.edu** if you have a positive story to tell.

Enjoy the year, it is your choice.

WHETHER YOU
THINK YOU CAN,
OR THINK YOU CAN'T.
YOU'RE RIGHT.

(HENRY FORD)

RECENT HEADLINES

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

FDA Clears Sangamo's SB-525 Gene Therapy for Investigational New Drug

NBC Updates Iron Max, Superhero Boy with Hemophilia

FDA Approves Adynovate to Treat Children and for Surgeries

Roche's ACE-910 Succeeds in the First of Three Final Stages of Clinical Trials

Biogen Approves Spin-off Hemophilia Business Bioverativ

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 then find the **RESOURCES** tab, and go to the **NEWSROOM** page. Find other stories at our Facebook page at www.facebook.com/ColoradoHTC/

UPCOMING EVENTS

Mark Your Calendars:

Feb 15: Self-Infusion Clinic Series at HTC

Feb 17-19: Education Weekend & RMHBDA Annual Meeting-Bozeman, MT

Feb 18: Backpacks & Bleeders Indoor Rock Climbing-Colorado Springs

Feb 20: Clinic and Admin offices closed for President's Day

Apr 15-16: Education Dayz-Lone Tree, CO

May 29: Clinic and Admin offices closed for Memorial Day

Jun 16-18: NHF CO Family Camp

June 16-18: RMHBDA Family Camp

July 14-15: Mile High Summer Camp-Leadership Retreat

July 16-21: Mile High Summer Camp

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

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