

The Clotting Connection

A Newsletter for Families with Bleeding and Clotting Disorders

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Hemophilia and Thrombosis Center
UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS



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Children's Hospital Colorado

HTC TELEHEALTH UPDATE



With the recent uptick in cases of the COVID-19 virus, our HTC has been adapting to maintain the highest quality of care and a safe environment for both our staff and patients who come into our clinic. We thank all of our patients who have adapted with us to using telehealth services during this pandemic. We appreciate your flexibility as we strive to deliver the same quality of patient care in a slightly different modality.

In the upcoming months, we will be converting our telehealth visits to the Vidyo system, which will closely integrate into the MyChart feature of your electronic medical record. In the near future, all newly scheduled telehealth visits will be based on this technology and you will be notified about your appointment format during scheduling. This changeover will allow for a more seamless telehealth visit across the board. The plans are in place for this system to begin early in January of 2021, so be aware we will be scheduling these telehealth visits soon.



If you haven't already, we strongly encourage individuals to sign up for [MyChart](#). MyChart has benefits beyond supporting our future telehealth needs. It allows you to see most of your laboratory values and provider notes, as well as providing a secure email-like messaging system with your providers at the University of Colorado Hemophilia and Thrombosis Center. When our system is fully shifted over to using Vidyo for our telehealth visits, you will need to access it through MyChart.



Image: Freepik.com

We thank all those who have worked with us as we all navigate new ways to connect and manage your healthcare needs. Contact us if you have questions about meeting with us via telehealth.

To learn more about MyChart and how to sign up, see mychart.childrenscolorado.org to begin the process. When signing up for the first time, you will need an access code. Our HTC can provide a code for you to get started. **Please contact our front desk for assistance when signing up.** For those who already have access, watch for more information soon about connecting with us via the Vidyo system. For questions about MyChart, please see the [Frequently Asked Questions section here](#). MyChart is available in both English and Spanish.

If you need any assistance in navigating the sign up process or if you have questions, please contact us at our front desk at (303) 724-0724 or toll free at (888) 297-0724.

We thank all our patients for their efforts in keeping those around them safe in this very unusual time. We hope this new shift can be a flexible and powerful resource for our patients going forward.



Image: Freepik.com

Get ready for telehealth with Vidyo by signing up at MyChart.

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



Go to facebook.com/ColoradoHTC



Go to twitter.com/HTCColorado



Website: Go to

medschool.cuanschutz.edu/hemophilia-thrombosis



Email:

HTC.Newsletter@ucdenver.edu

CELEBRATING HOLIDAYS 'SOCIAL DISTANCING' STYLE

This year has been challenging and as we head into the holiday season, it may feel particularly disappointing with increased state and local regulations that may keep us away from those we love. If your Thanksgiving or other upcoming holidays are looking lonely or glum, how can you adapt to make it special despite it all?

Find Virtual Ways to Celebrate

If your family is spread out or unable to be together this year, there are many fun ways to make a virtual [call with family a special time](#).

Find your format (Zoom, Skype, Facetime, etc.) and prepare in advance. Send out invitations with a link and be familiar with the tools to make it easy and fun for all. If some relatives don't know how to use video technology, reach out early and practice so everyone can see their loved one's faces on your special day.

[There are many great ideas online with games, competitions, and ways to play along together virtually to make it a special event](#). You can plan to sit down to eat at the same time and have dinner 'together' virtually. Breaking bread together is a long-held holiday tradition, and with a little creativity that fits your style, you can still have a fun and memorable meal.

Send Care Packages or Gift Boxes

Think ahead and prepare a small package with gifts or treats that can be enjoyed from a distance. You can include uplifting or funny notes, favorite snacks, small games to play, matching napkins, a special memento, or family tee-shirts to tie a virtual celebration together.

Having something physical to hold or use that arrives in the mail can bond family and friends together as they celebrate from afar.



Learn New Recipes

Many of our traditional holidays revolve around food, and that is not necessarily something that needs to change. If you always went to Grandma's for dinner, maybe it's time to give her a call and find out just how she made that stuffing or pie then report back on how it went! Some recipes take time and patience to learn, but knowing you learned direct from the source and with their secret sauce, can make those treats extra special in future years.



Then again, if you don't really like a traditional family recipe, 2020 is the year for you to try new things! Whether it is a new way to cook something you love, or a dish you've never tried, embrace the opportunity to turn this year into a time of new culinary discovery.

Create New Traditions

As disappointing as it may be to have to cancel traditions you have done for years, [now is a great time to create some new ones](#). Instead of the family Turkey Bowl, you could watch the game and video chat your family or friends as you watch. Or perhaps you could pick your favorite movie franchise and binge watch on the long holiday! This year would be a great time to start playing board games together, doing a puzzle, or [creating a scavenger hunt](#).

Discover the joy of reading a favorite book aloud together, or telling stories by the fire. Map out your own 5K and take the family around the neighborhood instead of the Turkey Trot. Find ways to volunteer safely: a local food drive or a donation center could use support.

Be creative, [search Pinterest](#), Google ideas, and look for the silver lining, and be sure to connect with those you love in your own unique way.

**Pediatric
Stroke Parent
Support Group**
**VIRTUAL ZOOM
Meeting**
**Tuesday
Dec 8, 2020
6:30-7:30 pm**

PEDIATRIC STROKE SUPPORT GROUP

Our Pediatric Stroke Parent Support Group is now meeting online! We've missed visiting with our pediatric stroke families in person, but to stay safe we'll be meeting online for a while longer.

Please join us for our next online meeting on **Tuesday, December 8th from 6:30-7:30 pm on Zoom**. We will be having a fun, holiday, virtual celebration!

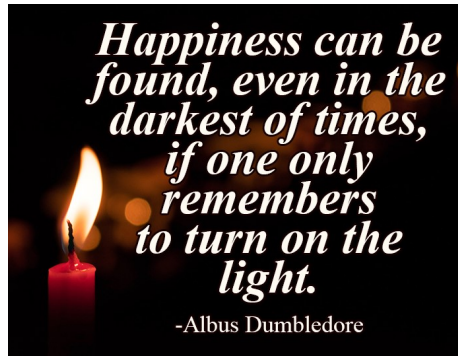
This group meeting welcomes everyone in the family to join. Your child does not need to be treated at our center to attend.

To join, please RSVP by contacting us at strokesupport@ucdenver.edu or (303) 724-8520. Follow us on Facebook for the latest on our meetings at www.facebook.com/Colopedsstroke. We hope you can come have fun with us on Tuesday, Dec 8th!

FINDING JOY THROUGH GRATITUDE

By Whitney Tedeschi

The great character Albus Dumbledore of Harry Potter lore stated, “Happiness can be found, even in the darkest of times, if one only remembers to turn on the light.” This quote from the third installment of the Harry Potter Movies rings true to many of us, but what does that mean as we navigate the current pandemic? How do we find that happiness, how do we turn on that light?



I believe gratitude can be a light switch to illuminate joy and happiness during these dark and uncertain times. Research shows that practicing gratitude, writing down a few things you are grateful for each morning and/or evening can positively improve your physical and emotional health. It can reduce anxiety and stress, thus positively impacting just about everything else.

Expressing gratitude does not mean you ignore the challenges you're facing or forget those you have already overcome; those are important to pay attention to. Expressing gratitude just brings to the forefront what has gone well for you that day, what has sparked joy for you each day and what you are thankful for. It could be

as simple as being excited you made a perfect cup of coffee or being thankful for having witnessed a few minutes of the sunset during your commute home. There is no doubt that taking a deep breath and acknowledging even one thing that went well in your day can help to positively reframe your daily outlook and ultimately help your health.

Reframing means to slightly alter how we view something but doesn't mean taking things out of your picture. Reframing simply encourages reorganizing your picture in a way that is meaningful and helpful. In this sense I don't urge you to ignore the challenges you've faced, to brush them aside, but to reframe your day in a way that both acknowledges the obstacles you've endured and also the bright spots you've enjoyed.



Thanksgiving is the perfect time to practice gratitude. Each of us has something to be thankful for and the practice of acknowledging those positive things can truly help “turn on the light” during these very difficult times.

How Can You Express Your Gratitude?

Write Thank You Notes

Expressing gratitude to others by a handwritten note in the mail, a kind e-mail, or a friendly text can mean the world to someone. And the act of pondering your gratitude to that person, writing it out, and sending it out can nurture your own happiness as well as strengthen your relationship with that person. [Studies have found that writing a note can lift your spirits and those of the one you send it to, it's a win-win!](#)



Keeping a gratitude journal and writing thank you notes are wonderful ways to express gratitude.

Keep a Gratitude Journal

The gratitude journal has long been a tool of therapists, parents, and religious leaders as a way to refocus or reframe your mindset. Just jotting down 3-5 things a day that you were thankful for, whether big or small, seems to have a positive impact on outlook and health. [Research shows that the act of writing these things down can be a powerful means to benefiting from this exercise.](#)

Some great ideas on how to keep a gratitude journal [can be found here.](#)

Count Your Blessings

Taking time out to ponder things that are good about your life on a regular basis is a great opportunity to feel gratitude in your heart. If you meditate or pray, [taking a portion of this time to focus on things you are grateful for can leave you feel uplifted and happier.](#)

Share your Gratitude Verbally

We may be unable to visit with friends and family, but technology allows us to call, chat, text, video call, and email one another with ease. Take the time to call someone you care about and regularly express your gratitude to them. The moments where you can share these feelings of gratitude [can build your relationship and reinforce your focus on the good things in your life.](#) Take time today to improve your health with an attitude of gratitude!



Hugging those you love is a great way to express gratitude, and once the pandemic eases, hugging can be back on your bucket list!

RECENT HEADLINES

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

Study Finds Passive Stretching, Manual Therapy Helps Joints of Hemophilia Patients

Results Published from Patient Satisfaction Survey Show Positive Reviews of HTC's Nationwide

Data Shows Hemlibra Improves Quality of Life for Children With Hemophilia A

Study Finds Good Long-term Outcomes After Knee Replacements for Hemophilia Patients

NIH Awards \$1.5 M Grant to DNA Medicine Institute to Develop Rapid Test

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. Go to medschool.cuanschutz.edu/hemophilia-thrombosis/resources/newsroom to read more. We also share news on our [Facebook](#) and [Twitter](#) accounts.

UPCOMING EVENTS

Mark Your Calendars:

Please note. These dates may be tentative and subject to change due to the COVID-19 pandemic and restrictions. Please check appropriate websites for confirmation of events.

Nov 26-27: HTC Clinic, Pharmacy, and Admin Offices Closed for Thanksgiving Holiday

Dec 8: Pediatric Stroke Parent Support Group-VIRTUAL

Dec 24-25: HTC Clinic, Pharmacy, and Admin Offices Closed for Christmas Holiday

Jan 1, 2021: HTC Clinic, Pharmacy, and Admin Offices Closed for New Years Day.

See more at our Events Page on our website: medschool.cuanschutz.edu/hemophilia-thrombosis/resources/events-calendar

Hemophilia & Thrombosis Center

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Web page:
medschool.cuanschutz.edu/hemophilia-thrombosis

PLEASE
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