It is no secret that 2020 has been a challenging year for us all. During these times, the resiliency of our community has shone brightly. From virtual camp, educational webinars, even a virtual strategic planning process, the dedication of our volunteers, health care providers and staff continued to thrive.

Even amidst a pandemic, the CHS continued to hold multiple rounds of consultations with stakeholders to ensure the updated Canadian Integrated and Comprehensive Care Standards for Inherited Bleeding Disorders was endorsed by all five health care provider and patient groups in May 2020. The standards were published and widely distributed in June 2020. A self-evaluation checklist was also developed to accompany the standards and is now being used by treatment centres. The goal of the National Standards of Care is to ensure patients benefit from receiving optimal and consistent care, no matter which centre across Canada they visit – essential now more than ever.

Following the approval of Hemlibra for patients affected by an inhibitor, the work to secure access to innovative therapies for patients without inhibitors continues. It is our hope that the drastically improved health outcomes and quality of life now experienced by inhibitor patients will be available to the widest population possible.

While the COVID-19 pandemic brought the cancellation or postponement of several key programs such as the Inhibitor Workshop and CODErouge – the 3rd Canadian conference on bleeding disorders in women, we are proud of the increased contact and how communication with our community has grown during this time. Our extensive use of videoconferencing software (which we have used for years for our board meetings) uniquely positioned us to continue our good governance at a time when we needed it most. Our increased presence on social media allowed us to connect with our community in a more informal and frequent manner.

One of the biggest decisions the CHS made this year was to move forward with our strategic planning process at the onset of the COVID-19 pandemic. As the CHS’ efforts continue to shift more and more to advocacy and standards of care, this was a timely decision and helped assist the CHS in rethinking the way we communicate and support our community during this time.

As we look forward to a new year, we remain hopeful that we will once again be able to gather together and celebrate all the work we have done to ensure that the vital work of the CHS continues, as we advocate for the best treatment and care for all.

With gratitude,

Paul Wilton
President

Hélène Bourgaize
Co-Executive Director

Deborah Franz Currie
Co-Executive Director