

ADVOCATING FOR CHILDREN IN A PANDEMIC



This year has challenged every facet of life- requiring us to adapt, grow, think strategically and look outside of our comfort zone to find creative ways to get our job accomplished. Whether you are a pediatric provider treating patients with a chronic disease in the midst of a pandemic or a state or federal policymaker opening your eyes to the challenges of your constituents, we have all grown but we need to continue to evolve to best meet the needs of children.

At Children's Hospital & Medical Center (Children's), our training, preparedness and heavy focus on quality and patient-safety allowed for swift adaptation in the midst of the COVID-19 outbreak. Flexibilities offered with Nebraska Department of Health and Human Services (DHHS) and Governor Pete Ricketts' (R-NE) direct health measures (DHMs), we were able to design a Respiratory Assessment Center (RAC) in our short-stay unit- completely isolated from the hospital tower, protecting our patients and staff in-house from exposure of COVID-19.

We abided by the governor's DHM in March restricting surgical procedures to protect and maintain adequate levels of personal protective equipment (PPE), ventilators and critical care beds. Weekly we maintained dialogue with Governor Ricketts and Chief Medical Officer of Nebraska Dr. Gary Anthone, advocating for the unique needs of children and explaining there was no such thing as an "elective" procedure for children.

As we continue to navigate change it is becoming more important than ever to use your voice and advocate for children. We often heard children were "unharmed" by COVID-19, but Children's drove the message to stakeholders that children are impacted, whether directly or indirectly, by the virus. We continue to work with partners in the schools across the state, state agencies, local, state and federal lawmakers, public health departments and other critical stakeholders to monitor outcomes, best practices and make sure the needs of children are not secondary.

The Nebraska Legislature took an extended recess in March, but asked senators to return in August to finish critical work this session. With proper safety measures in place, Senator Bob Hilkemann (R-Dist. 4-Omaha) and Senator Carol Blood (D-Dist. 3, Bellevue) successfully advanced Children's priority bill- [LB825](#), adding Spinal Muscular Atrophy (SMA) to the newborn screening panel in Nebraska. The bill, amended to [LB755](#), will ensure Nebraskans receive immediate treatment for SMA before symptoms even occur. Typically a child would not show signs or symptoms of SMA until 6 months of age or later, and with new FDA approved drugs available, this bill ensures that child can develop like their peers and lead a healthy life.

Next year, we are looking forward to working with Senator John Arch (R-Dist. 14, La Vista) as he uncovers the future opportunities for telehealth and what relaxed guidance measures should/could remain post-COVID to increase access to care. Additionally, we are working with key senators as we determine next steps outlined by Dr. Don Coulter and the Child Health Research Institute (CHRI) at the 2020 Pediatric Cancer Research Symposium. The high incidence of pediatric cancer in Nebraska is a tragic reality that will require focus and determination by the Legislature.

Children's bill watch list is available on our webpage - Childrenomaha.org-under Advocacy & Outreach- [Policy Advocacy & Government Affairs](#) – Legislative Updates right-hand sidebar – [Children's Bill Watch List](#).