

Star Supporters

Support from Maine Elks Association Surpasses \$4 Million in 2017!



Since MCCC's inception in the mid 1980's, the Maine Elks Association has been our program's single largest supporter – and without their continued support, MCCC would not be what it is today. From the very beginning, the Maine Elks have made MCCC their Statewide Major Project, committing significant time and energy throughout the year to fundraising in support of the program.

The Maine Elks Association's annual State Convention is always an exciting event for MCCC because it is here that the Elks announce their yearly fundraising total on behalf of the program. At the 2017 State Convention, not one but two outstanding milestones were reached relating to the Elks' support for Maine Children's Cancer Program!

On Saturday, May 6th, with members of the MCCC Board and Philanthropy staff present, as well as MCCC patient Seth Jones and his family, the Maine Elks presented their largest check to date to Maine Children's Cancer Program: an astounding \$242,717! This amount represents a year's worth of fundraising by the Maine Elks statewide. And it gets even better: after several final contributions were counted, the yearly donation amount actually increased to \$257,624!

Not only was this amount the largest ever raised by the Maine Elks for MCCC in one year, but it also pushed the Maine Elks' lifetime fundraising total for MCCC past the \$4 million mark. As Elks gathered to toast the incredible milestone, it was very clear that they have no intention of resting on their laurels; enthusiastic chants of "5 million" rang out.

Words cannot begin to express our gratitude for being the Major Project of the Maine Elks - thank you for being such incredible partners and wonderful champions for children fighting cancer.

Meet Our Patients

An Amazing Season of Honoring Our Heroes!

The third season of Anthem's Heroes at Hadlock was a great success, filled with unforgettable moments and a smorgasbord of Sea Dog Biscuits, thanks to Anthem BlueCross BlueShield, the Portland Sea Dogs, MaineHealth and our incredible patients and families who so kindly represented our program. All four of our heroes have such powerful stories, and are more than deserving their time to shine and to be celebrated in honor of their fight against cancer.

We kicked off the 2017 program on May 26th with MCCP Day at the Sea Dogs, where our 2017 Slugger Kid, Seth Jones, participated as our first Anthem's hero of the season. Our next hero was Nate Wade, a.k.a Super Nate, who ran the bases with his big brother Connor on June 25th. Rosy Young was next at the plate on July 22nd, timid at first, then leaving her mother, Karale, and father, Josh, to chase after her! Our final Anthem's hero of the 2017 season was Alice Denecker, who flew around the bases and gave her grandfather, Ed, a run for his money this past weekend on August 6th.

Seth Jones



Seth's journey with cancer began at only 6 years old when he was diagnosed with Stage 4 Wilms tumor at Boston Children's Hospital. Wilms tumor is a rare kidney cancer found mostly in children. Shortly after the diagnosis, the Jones family got terrible news: Seth's kidney needed to be removed right away and the cancer had spread to his lungs.

One week after his surgery, Seth's care was transitioned to the Maine Children's Cancer Program (MCCP) in Scarborough. He was cared for by Dr. Jessica Pollard, who prescribed a 32-week chemotherapy and radiation treatment program. The days and weeks during treatment were filled with emotional and physical challenges for Seth and his family, but the staff at MCCP supported them well

beyond their call of duty. And when Seth was going through tough times, the staff was always there to hold his hand and wipe away his tears. Seth still speaks fondly about his care team and hugs everyone when he goes to MCCP for follow-up visits.

Now 8 years old, Seth is a cool 2nd grader in Rochester, New Hampshire, who enjoys the Cub Scouts and technology. It even appears that some of MCCP's magic has rubbed off on him too! Along with his big brother Wade, he's wowed audiences with magic shows at venues like the Rochester Opera House, Camp Sunshine and aboard the MV Mount Washington ship.

Seth and his family will be forever grateful to MCCP and draw strength from the days when the caregivers were there to help. In 2017, Seth will serve as Slugger Kid, ambassador for the Strike Out Cancer in Kids campaign, a partnership between MCCP and the Portland Sea Dogs.

Nate Wade



In April of 2015, just after he turned 4, Nathan Wade (a.k.a. Super Nate), was diagnosed with Ewing's Sarcoma, a cancerous tumor that grows in the bones or tissue around the bones. He immediately began treatment at Maine Children's Cancer Program (MCCP). Nate had to be brave for 10 months while he endured numerous tests, a procedure to install a port in his chest that pumps medicine into his veins, an aggressive chemotherapy regimen as well as surgery to remove the tumor and sections of his ribs on the right side of his body.

Because of the treatments, Nate had no appetite and lost weight. He developed large blisters on his feet, consistently ran fevers and eventually lost his hair. One of the most traumatic parts of his treatment was getting into and out of the port in his chest, which had to be done dozens of times. But the MCCP team, along with the wonderful oncology nurses at The Barbara Bush Children's Hospital and the amazing child life specialists, knew how to get smiles out of Nate even on his worst days. Dr. Weiss, Nate's primary oncologist, bonded with him over a shared love of Star Wars.

By the end of treatment, Nate had transformed from a shy, scared, depressed boy to the mayor of the floor. He could often be found riding his IV pole around the Barbara Bush wing like a seasoned skateboarder. That is until he got a speeding ticket from the nurse's station.

Today, Nate is 6 years old and doing great! He's enjoying his favorite pastimes, including soccer, drawing, coloring, hanging out in the water and most of all skiing. Nate LOVES to ski. Nate had large support groups from the greater Sugarloaf and Brunswick areas that helped him and his family tremendously throughout his journey.

On most weekends during the winter, you'll find Nate at his home mountain, Sugarloaf, practicing his skiing turns (except when he travels to Shawnee Peak to help support MCCC). During the summer, Nate prefers to be at the lake or at the ocean relaxing in the water, and he always takes time to smell the flowers.

Rosy Young



In the fall of 2014, Rosy Young was only 4 years old when her parents noticed something was wrong with her right eye - it was pointing directly inward. After visiting a pediatric ophthalmologist – a doctor who treats children's eyes – Rosy got an MRI and was diagnosed with stage II embryonal rhabdomyosarcoma, a disease in which cancer cells form in muscle tissue. It was then that Rosy and her family met with cancer specialists at Maine Children's Cancer Program (MCCC) and The Barbara Bush Children's Hospital (BBCH).

For 11 months, Rosy underwent countless chemotherapy infusions, hospital stays, emergency room visits and blood draws. Through it all, she was a true warrior. Her fighting spirit won over the staff at MCCC and BBCH as she made numerous friends and touched many lives.

Due to Rosy's never-give-up attitude and the incredible support and treatment she received at MCCC and BBCH, this month Rosy celebrates two years cancer-free! She also welcomed a baby sister, went on her

Make-A-Wish trip to Disney World, excelled in school and will be starting the second grade this fall.

Rosy's father, Josh, is forever grateful for MCCC and BBCH. "Never have we been surrounded by more love, care, knowledge and support. They have truly saved Rosy's life and become so dear to our family's hearts."

Alice Denecker



In October 2011, Alice was only 3 years old when her mother discovered a lump on her back during a bath. Less than 24 hours later, Alice was diagnosed with stage 4, high-risk neuroblastoma, a cancer of the nervous system. The cancer had formed a tumor in Alice's abdomen and spread to several spots in her bone marrow. Since that day, Alice has undergone two surgeries and many treatments including a stem cell transplant and countless rounds of radiation and chemotherapy.

From the moment of her diagnosis, Alice has been under the care of the Maine Children's Cancer Program (MCCC). First, as a patient of Dr. Ashley Speckhart and then Dr. Jessica Pollard. While Dr. Speckhart and Dr. Pollard have led the charge in Alice's care, all of the doctors, nurses, social workers, child life specialists and staff at MCCC have played an invaluable role in Alice's treatment. They've provided Alice with cutting-edge cancer therapies as well as a lot of encouragement, lollipops and special cuddles with Daisy, the clinic therapy dog.

Thanks to the dedicated, expert care Alice got at MCCC, she's now 9 years old and excited to start fourth grade in the fall. She enjoys playing drums, singing and drawing. But her favorite pastime is riding horses. One day, Alice hopes to be a professional horse jumper or a veterinarian. Alice has become a huge fan of the Boston Red Sox and the Portland Sea Dogs, and she was thrilled to be honored at Hadlock.

Clinic News

Hyundai's \$50,000 Grant Supports MCCC Research



On Thursday, June 29th, Hyundai Motor America visited the Maine Children's Cancer Program clinic in Scarborough to present a \$50,000 Hope Grant to support childhood cancer research and programs dedicated to improving the lives of children who are fighting cancer. Maine Medical Center is one of 25 recipients of this year's award, which is given to pediatric oncology departments at select children's hospitals nationwide. The Maine Children's Cancer Program will use the funding to support the incredible research efforts of Dr. Weiss and Dr. Pollard.

Dr. Weiss is primarily focused on the identification of novel targeted therapies to improve clinical outcomes in tumors known as soft tissue sarcomas, particularly in the Adolescent and Young Adult (AYA) age group. This population is often underrepresented in clinical trials and tend to have inferior outcomes compared to their younger or older counterparts. He is currently the co-chair of a National Cancer Institute (NCI)-sponsored clinical trial which is evaluating the feasibility of combining a novel targeted agent (pazopanib) to the standard treatment approach of surgery, radiation and chemotherapy in Non-Rhabdomyosarcoma Soft Tissue Sarcoma (NRSTS). This study is the first ever NCI-sponsored collaborative study co-written and conducted by both a pediatric (Children's Oncology Group) and adult cancer (NRG Oncology) consortium group and represents an unprecedented opportunity to advance the treatment of AYA patients with NRSTS. This trial opened in 2014 and is anticipated to enroll 340 patients throughout North America. The study is currently open at over 300 centers. Dr. Weiss is also the principal investigator for a second clinical trial funded through the Desmoid Tumor Research Foundation. This study is examining the role of sirolimus in the treatment of children and young adults with higher risk desmoid tumors. Sirolimus directly targets and inhibits a pathway that may be critical for the development and growth of these tumors. The study is currently open at 6 centers throughout the United States. To date, 8 patients have been enrolled. It is his hope that the results of this trial could be leveraged to

support a national collaborative study, such as one run through the Children's Oncology Group, in children and young adults.

Dr. Pollard's research efforts are geared towards Acute Myeloid Leukemia. Approximately 1000 children are diagnosed with AML each year; 40% of these children will not be cured of their disease, suggesting novel treatment strategies are needed that utilize knowledge of disease biology to optimize treatment. As a member of the Children's Oncology Group AAML1031 study committee, Dr. Pollard is studying novel approaches for improving outcomes for greater than 1500 children with AML. She currently provides oversight of patients with FLT3/ITD+ AML, a high-risk disease feature historically associated with 20% overall survival. These children are receiving the targeted agent sorafenib as part of their therapy given her previous research that reported, in a small series of pediatric AML patients, that this drug may be particularly effective for this subset of patients. She will report on the safety and efficacy of this drug when the study completes this summer. As vice chair of AAML1031's successor study (phase III study COG AAML1731), slated to open in 2018, Dr. Pollard will utilize knowledge gained from the AAML1031 experience to conduct a follow up study for children with AML that has strong biologic rationale. This trial will expand our FLT3 inhibitor experience to include a broader scope of FLT3 mutant patients and utilize a more targeted second-generation FLT3 inhibitor.

Dr. Pollard also has a strong track record of collaboration with laboratory investigators and has aided the translation of laboratory findings into our therapeutic approaches. Specifically, her research has defined various disease features that put children with AML at higher or lower risk for relapse and has aided our ability to develop "risk-based" therapeutic approaches for our patients- treatment that will ensure the greatest likelihood of curing their disease while minimizing, as much as possible, excessive toxicity to the body.

The Passion and commitment of our physicians to research-based care, fueled by funding from programs like Hyundai Hope on Wheels, keeps Maine Children's Cancer Program at the forefront of pediatric oncology programs nationwide.

Community Support

This September, Help Maine Go Gold!



September is National Childhood Cancer Awareness Month, and the official awareness color is Gold. September provides a powerful opportunity to bring childhood cancer into the spotlight – together, we can help raise awareness for a disease that is not rare (roughly 16,000 children in the United States will be diagnosed with cancer this year) and that is underfunded when it comes to research to help find a cure.

During the month of September, there are many ways for those whose lives have been touched by childhood cancer to become involved, and we invite you to join the movement! Whether it's through participating in an event like the MCCP Walk or the Hugs From Hayley 5K Race, supporting an organization like MCCP that actively participates in childhood cancer research, or wearing a gold awareness ribbon, your actions will make a large and lasting impact on the fight against childhood cancer.

Another way to get involved is to lend your support to a powerful movement currently underway: in the words of local childhood cancer fighter, Hailey Steward, "Go Gold Maine, Just Do It!" Hailey and her mother, Tabaitha, have set out on a mission to ask all 455+ towns/cities/communities in Maine to issue a statement proclaiming September as Childhood Cancer Awareness Month. 10 year old Hailey, who continues to fight B-Cell Acute Lymphoblastic Leukemia (ALL) like the force of nature that she is, has made it her mission to bring about statewide awareness for childhood cancer and how the disease affects children just like her. With help from other parents of childhood cancer patients here in Maine, there are currently over 30 towns who have agreed to issue the proclamation!

Please help Hailey reach her goal of turning Maine Gold in September by approaching your town office and asking that they issue the proclamation. A sample proclamation, drafted by MCCP parent, Tim Wade, can be found here:

<http://docs.google.com/document/d/18qmHLM6n8xX5HDnaakmxtS3m3eR6eObuiK3ECIKNMgE/edit>

More information on Hailey's mission can be found at <http://haileyhugs.org/maine-goes-gold>.

No matter how you choose to support Childhood Cancer Awareness Month, your participation will pay tribute to the young heroes among us who bravely fight cancer.