

CHILDREN'S SPOTLIGHT:

# Cancer and Blood Disorders Program



Susan Sencer, MD

Children's  
Hospitals and Clinics  
of Minnesota

[childrensMN.org/cancerandblood](http://childrensMN.org/cancerandblood)

# 30 years of leading the way

At Children's Hospitals and Clinics of Minnesota, we're experts in treating kids with cancer and blood disorders. In fact, Children's is the largest pediatric cancer and blood disorders program in the Upper Midwest, caring for more than 55 percent of children diagnosed with cancer or blood disorders in Minnesota, and 70 percent of those diagnosed in the Twin Cities.

We not only treat the disease, we support the patient and family by offering advanced, individualized care for children, teens and young adults — even if it's a rare, relapsed or recurrent cancer.

## INNOVATIVE CARE APPROACH

**One visit. Many specialists.** Multi-specialty clinics allow our patients to visit all their specialists during one clinic visit. We have multi-specialty clinics, including teen bleeding and gynecology, vascular anomalies, hemophilia, sickle cell disease, brain and spinal cord tumor, and the immune dysregulation clinic.

**Kids are hospitalized less.** We give chemotherapy in our clinic or at one of our two satellite clinics to reduce hospital stays and support normal routines for the patient and family.

Our nationally recognized sickle cell pain management team has reduced hospital admissions for sickle cell disease pain by approximately 50 percent and reduced their length of stay by nearly 50 percent.

**Good food is good medicine.** Nutrition is especially important during treatment and recovery. That's why we have a full-time dietitian within our outpatient area.

**Movement supports healing.** Physical therapists specialized in cancer care and chemotherapy-related issues work with kids during appointments and in the clinic gym to promote normal motor development during treatment and recovery.

**School and learning resources.** We can connect with teachers and classrooms after a diagnosis to promote understanding and success at school. Additionally, neuropsychologists work proactively with patients, families and schools when needed to help patients reach their maximum intellectual potential.

**A one-of-a-kind facility.** Children's C.H. Robinson Infusion Center is the largest of its kind in the state, with 14 private rooms and more than 3,400 outpatient visits each year. All of our clinic and hospital rooms are private and spacious enough to accommodate the patient, family and care team.



## MEET JAELA, AGE 12

On the ice, Jaela was unstoppable. An elite athlete and top-ranking goalie, she consistently gave 100 percent to protect the net and support her team.

But her biggest competitor came off the ice, when she learned she had acute lymphoblastic leukemia. The same day she was faced with this devastating diagnosis, she also started her 158-week treatment plan at Children's, an obstacle she's confident she'll overcome.

Though she remains in treatment, Jaela is back to playing hockey six days a week. Now, she not only has her teammates behind her, she also has her care team at Children's walking with her, every step of the way.

*"There was no candy coating it. We knew she had leukemia. But, we knew we were at the best place we could be. You could feel it in the walls."*

— Jaela's mom, Katie

# Children's cancer and blood disorders program by the numbers



We participate in **100+ RESEARCH STUDIES** and have the largest clinical research staff in the region.



Research shows that adolescents and young adults with pediatric cancers typically experience **SIGNIFICANTLY BETTER OUTCOMES** in pediatric facilities, using pediatric protocols.

## OUTCOMES MATTER

- Some of the **HIGHEST SURVIVAL RATES** among leading U.S. children's hospitals.
- Some of the **LOWEST LENGTH-OF-STAY RATIOS** in the country.

**WE TREAT OVER 85%** of Minnesota children and teens with **SICKLE CELL DISEASE**.



**24/7 ACCESS** to hematologists and oncologists.



**NEARLY 97%** of **PATIENTS SAY THEY WOULD RECOMMEND CHILDREN'S** cancer and blood disorders program.

**CHILDREN'S HAS THE ONLY**

- Teen hematology and gynecology program in the state.
- Two pediatric gynecologists in Minnesota.

**NEARLY 90%**

of our patients who are eligible **PARTICIPATE IN CLINICAL TRIALS** — placing us in the top 5% of programs in the U.S. for patient enrollment in clinical trials within Children's Oncology Group (COG) member institutions.



## Better journeys, better outcomes

Every patient's journey is unique — from the tests they need to the individualized treatments they receive. From the start, each patient meets with a physician and is assigned a health care team dedicated to the child through each stage of treatment and recovery.

### DIAGNOSIS AND TREATMENT

Phase one includes diagnosis and development of a personalized treatment plan.

### RECOVERY AND WELLNESS

Phase two includes the two-to-five year period after treatment. Visits include evaluation of possible side effects of treatment with an emphasis on recovery and wellness education.

### STAR CLINIC (SURVEILLANCE AND TESTING AFTER RECOVERY)

Phase three includes yearly visits with the STAR clinic team for monitoring and evaluation of possible side effects of treatment and disease recurrence. Wellness education and healthy lifestyle choices are emphasized.

## What sets us apart

**Access to the latest treatments.** Nearly 90 percent of our patients who are eligible for a clinical trial participate in one. If a new, effective treatment is on the horizon, we're among the first to know about it.

**An all-access pass to leading technology.** Children's is the only pediatric hospital in the Midwest using Visualase®, an ultra-precise, MRI-guided laser system for brain tumor and epilepsy surgeries. This high-tech approach minimizes pain and speeds healing.

**Integrative cancer care.** We care for the patient's physical well-being as well as body, mind and spirit by combining the best complementary and conventional medicine therapies.

**Emphasis on preserving fertility.** We work with teens and young adults receiving chemotherapy, radiation or surgery to preserve their fertility, an important part of their quality of life and future.

**Advancing the understanding of rare tumors.** As a leader in clinical research for rare diseases, we're the home of the International Pleuropulmonary Blastoma Registry and the International Ovarian and Testicular Stromal Tumor Registry.

**Care closer to home program.** Through partnerships with physicians in St. Cloud, MN and Hudson, WI, Children's cancer experts are able to provide convenient, coordinated care closer to home when possible.

# Complete cancer care

Children's houses the largest pediatric cancer program in the Upper Midwest, which means we're always prepared to deliver the latest treatments and services for patients and families.

## OUR SPECIALTY CANCER PROGRAMS

**Leukemia and lymphoma** — Children's cares for the majority of children diagnosed with leukemia and lymphoma in the state of Minnesota and is the trusted regional treatment center for many children in the five-state area.

**Brain and spinal cord tumor** — The largest pediatric central nervous system (CNS) tumor program in Minnesota, delivering complex care through a single visit in our comprehensive clinics in Minneapolis and St. Paul.

**Solid tumor** — One of the largest programs in the Upper Midwest. Therapies range from surgery and radiation to chemotherapy and stem cell therapy.

**Adolescent and young adult (AYA)** — Care doesn't stop at age 18. We provide education, monitoring, care and support to AYA patients with pediatric cancers — and research shows they do better following treatment protocols in pediatric facilities.

**Head and neck** — The largest head and neck program in Minnesota, with treatment results consistently ranking us among the best.

**Rare tumors** — Individualized treatment of children and adolescents diagnosed with a rare tumor, using the expertise of our specialists and consults with experts worldwide.

**Hereditary cancer** — Testing and counseling for children diagnosed with cancer as well as those whose family history indicates they may be at risk for developing cancer.



## GENOMICS

Understanding the DNA abnormalities of all cancers is important for planning the right treatment. The evolving field of genomics allows Children's to offer technologies that personalize cancer treatments and provide the best chance of a cure with minimum side effects.



## MEET CLOVER, AGE 4 MONTHS

A devastating diagnosis began with a diaper change when Keeley noticed a hard lump on her then three-month-old daughter's stomach. They landed at Children's where Keeley and husband Irving learned their third child, Clover, had cancer.

Shocked, Keeley and Irving knew they had two choices. Give in to despair and doubt, or trust the Children's team supporting them and bravely enter into the world of cancer treatment. They chose the latter.

Days after the diagnosis, Clover started chemotherapy. Today, she continues her chemotherapy treatment and the tumor is shrinking.

On the tough days, Clover's mood is brightened by nurses, including ER nurse Erin who wore clover covered scrubs, or by Boyd, a lovable therapy dog.

*"It's so wonderful to really know the team who is working so hard to make Clover well again. They're our angels."*

— Clover's mom, Keeley

# Experts in blood disorders care

Children's houses the largest pediatric blood disorders program in Minnesota, treating the majority of children and teens in the state. That puts us in a unique position to deliver the latest treatments children need and provide information and support to the entire family.

## OUR SPECIALTY BLOOD DISORDERS PROGRAMS

**Center for bleeding and clotting disorders** — Part of a nationwide network of federally funded Hemophilia Treatment Centers (HTCs) and the only program in the region focused solely on caring for children and adolescents with bleeding and clotting disorders.

**Hemoglobinopathy and sickle cell** — A nationally recognized program that treats 85 percent of children and teens in Minnesota and provides consultation about the disease to health care providers in the region.

**Anemia and other blood deficiencies** — Providing care and consultation with physicians from all over the region. From simple to complex, whatever level of care children need, we can help.

**Vascular anomalies** — One of only a few centers in the country dedicated to treating children with all types of vascular anomalies. That's why patients from across the Midwest and as far away as Alaska depend upon us.

**Bone marrow failure** — Evaluating, diagnosing and treating both inherited and acquired bone marrow failure. We participate in several national registries to help experts learn more about these rare syndromes and their treatment.

## ANTICOAGULATION MONITORING

Jennifer Lissick, PharmD, a pharmacist trained in hematology, was brought on board to establish a pediatric outpatient anticoagulation monitoring service for our patients. This is a cutting-edge, patient-friendly service that uses text messaging to improve adherence and ensure safety in monitoring.



Jane Hennessy, CNP, MPH



Stephen Nelson, MD

# What sets us apart

**We've seen it all.** We treat more than 1,500 Minnesota children and teens with blood disorders each year, including more than 85 percent of children and teens with sickle cell disease or hemoglobinopathies, and more than 80 percent of children and teens in Minnesota with a hemophilia diagnosis.

**Comprehensive care.** Our comprehensive care model brings together many specialists to see the patient in a single clinic visit, and has a proven record of improving health and reducing costs. We collaborate with community services to benefit the patient and family by offering summer camps, parent support groups and family retreats.

**Special care for young women.** The only teen hematology and gynecology program of its kind in Minnesota offering coordinated care, where patients can see both a pediatric hematologist and a pediatric gynecologist in a single visit.

**Telemedicine program.** Through an expanding telemedicine (virtual care) pilot program, providers are able to assess, monitor and treat established patients with hemophilia in their home.

## BLOOD TEST REDUCES TRANSFUSION NEEDS

The thromboelastogram (TEG) allows hematologists to measure how the blood clots and dissolves in real time.

This tool is superior to standard tests because it looks at how all of the components of the blood (clotting factors, platelets, and thrombolysis) interact to give a global picture of hemostasis. This technology is most useful for patients with bleeding disorders and has been shown to help reduce the need for transfusion.



Nicole Leonard, RN



## MEET DANYELLA, AGE 7

Danyella's parents were shocked when their baby girl was diagnosed with sickle cell disease after undergoing a newborn screening test.

Danyella's mom, Nicole, was referred by her primary care physician to Stephen Nelson, MD, at Children's hemoglobinopathy and sickle cell program. Nicole and her family, who are from the Caribbean, reside in Minnesota so Danyella can continue to get the care she needs at Children's.

Today, Danyella is a thriving, active seven-year-old. She goes to the Children's clinic every three months for a blood check. Her parents are grateful for everyone who cares for Danyella at Children's.

*"Dr. Nelson's presence assures us that everything will be great. He is more than a doctor, he is a great person."*

– Danyella's mom, Nicole

# Commitment to excellence

For more than 30 years, Children's cancer and blood disorders program has been focused on innovation, research and compassionate care by diagnosing and treating children, teens and young adults. With dedicated pediatric resources, technology, staff and facilities, our pursuit has led to some of the best outcomes in the nation.

The data below is derived from the Pediatric Health Information System (PHIS), a national comparative database in which children's hospitals across the country compare themselves to one another in key measures of overall health care quality.

## LENGTH OF STAY

### Better than expected: length of stay ratio

Length of stay is the number of days that a patient is hospitalized for care in a single visit. Children's average length of stay is nearly a full day less than the average of the 41 other hospitals in the PHIS database.

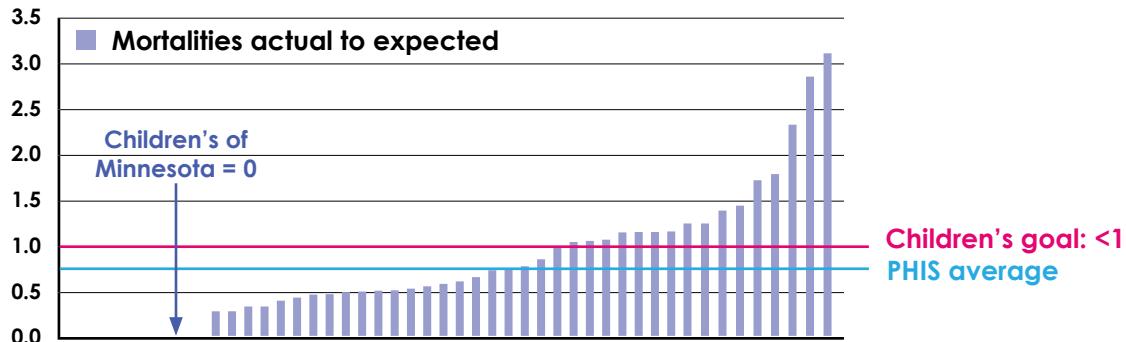
AVERAGE LENGTH OF STAY	Hematology	Oncology
Children's Hospitals and Clinics of Minnesota	3.27 days	5.4 days
41 other children's hospitals	4.25 days	6.08 days

## MORTALITY RATIO

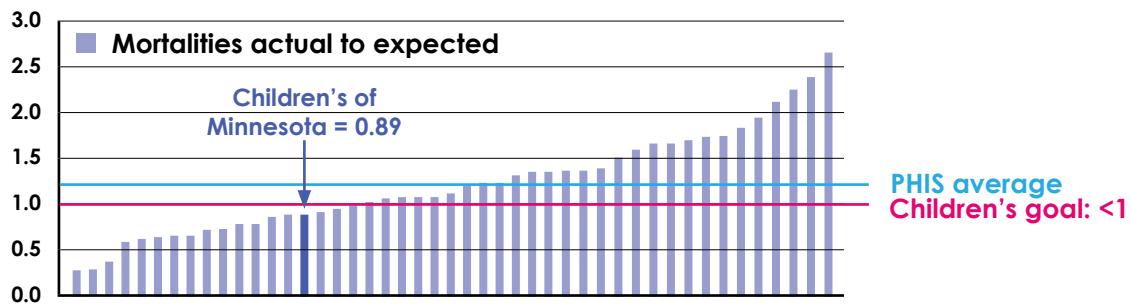
### Better than expected: actual to expected mortality ratio

Children's has one of the lowest actual to expected mortality rates, meaning there are fewer deaths than expected given the severity of illness of our patients. **A ratio less than one is preferable — the lower the number the better.**

ACTUAL TO PREDICTED HEMATOLOGY MORTALITY RATIO (2011–2013)



ACTUAL TO PREDICTED ONCOLOGY MORTALITY RATIO (2011–2013)



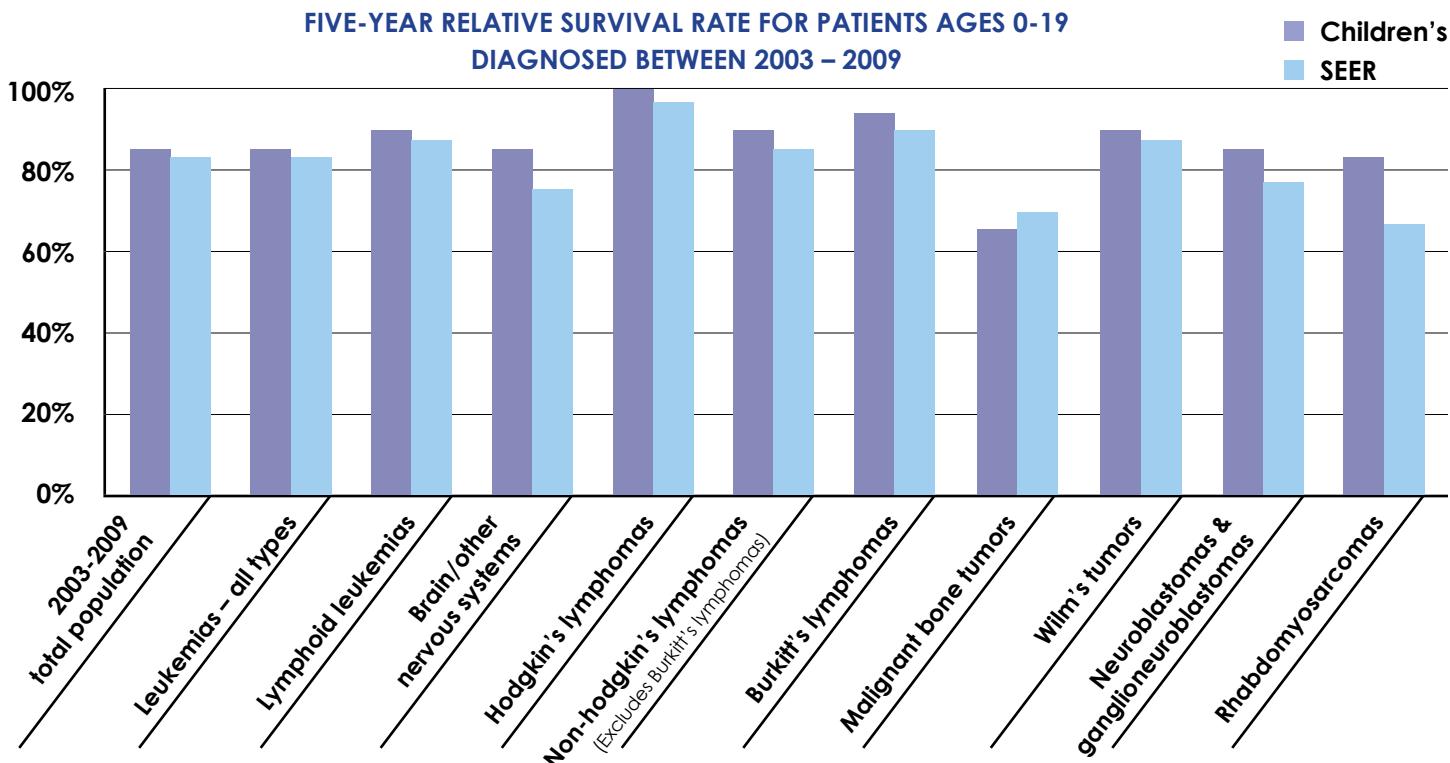
# Exceeding standards for patient care, quality, service and safety

## AMONG THE BEST

### How Children's cancer survival rates compare to SEER data from 18 cancer centers

The Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute collects and publishes cancer incidence and survival data from 18 cancer registries in the U.S.

Five-year cancer survival rates are calculated based on the year of diagnosis. Therefore, a child who is diagnosed in 2008 is evaluated for five-year survival in 2013. Children's has higher five-year survival rates in nearly all categories.



## MINUTES MATTER

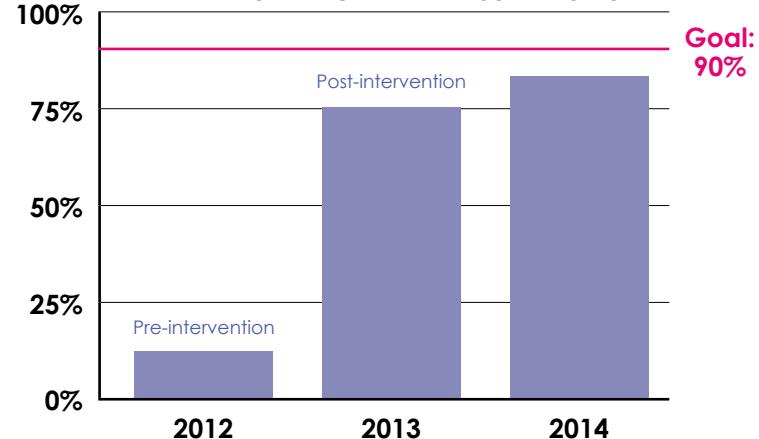
### Anitibiotic administration for suspected infection in the ED

Benchmark data: U.S. News & World Report asks that 90% of patients coming to the ED get antibiotics in less than 60 minutes.

Collaboration among the ED and the cancer and blood disorders team resulted in interventions that shortened the time frame in which antibiotics were administered after arrival to the ED.

Research shows this results in a decreased need for Intensive Care Unit (ICU) level care.

### CHILDREN'S PERCENTAGE OF ANTIBIOTIC ADMINISTRATION WITHIN 60 MINUTES



# One program, many experts

## PHYSICIANS



Anne  
Bendel, MD



Bruce  
Bostrom, MD



Julie  
Chu, MD



Stephanie  
Fritch Lilla, MD



Margaret  
Heisel Kurth, MD



Susan  
Kearney, MD



Nancy  
McAllister, MD



Yoav  
Messinger, MD



Stephen  
Nelson, MD



Joanna  
Perkins, MD, MS



Jawhar  
Rawwas, MD



Michael  
Richards, MD, PhD



Kris Ann  
Schultz, MD, MS



Susan  
Sencer, MD



Clark  
Smith II, MD



Maggie  
Skrypek, MD



Michael  
Sprehe, MD, MPH

**200** DEDICATED PROFESSIONALS

comprise our extensive team —

including physicians, nurses, case managers, pharmacists, rehabilitation therapists, dietitians, social workers, music therapists, massage therapists, child life experts, interpreters, and home care and hospice specialists, as well as professionals from many other disciplines.

## NURSE PRACTITIONERS



Kristen  
Appert, CNP



Melissa  
Christensen, CNP



Melissa  
Hansen, CNP



Jane  
Hennessy, CNP



Kimberly  
Jacobson, CNP



Mary  
Langevin, CNP



Mylynda  
Livingston, CNP



Linda  
Madsen, CNP



Kristin  
Moquist, CNP



Dawn  
Niess, CNP



Lori  
Ranney, CNP



Vicki  
Schaefers, CNP



Amy  
Wein, CNP



Jon Matters, RN

## Research that matters

At Children's, we focus on research and innovations that make a difference at the bedside. From improving day-to-day quality of life for children and teens to developing new pain management approaches and adopting top-of-the-line technologies, our research is completely kid and family focused.

### CLINICAL TRIALS

A clinical trial is a research study to see if a new treatment is safe and works better than the current approach. At Children's, most patients diagnosed with cancer who are eligible and provide consent to take part are treated in a clinical trial.

### FIND AVAILABLE STUDIES AND ARTICLES

View current studies open for enrollment at Children's:

[childrensMN.org/cancerbloodstudies](http://childrensMN.org/cancerbloodstudies)

Learn about cancer and blood disorders research:

[childrensMN.org/cancerbloodresearch](http://childrensMN.org/cancerbloodresearch)

### NATIONAL RESEARCH PARTNERS

Children's is one of the most active participants in the nation in the number of patients enrolled in clinical trials, which results in rapid deployment of new information. Our research partners span across the country and include:

- American Thrombosis and Hemostasis Network
- Centers for Disease Control and Prevention (CDC)
- The Childhood Cancer Survivor Study (CCSS)
- Children's Oncology Group (COG)
- Health Resources and Services Administration (HRSA) Hemophilia Treatment Center Network
- Health Resources and Services Administration (HRSA) Sickle Cell Demonstration Program
- International Pediatric Fungal Network
- Northern States Regional Executive Committee of Hemophilia Treatment Centers
- The International Ovarian and Testicular Stromal Tumor (OTST) Registry
- International Pleuropulmonary Blastoma (PPB) Registry
- Severe Chronic Neutropenia International Registry (SCNIR)
- St. Jude Children's Research Hospital
- The Neuroblastoma and Medulloblastoma Translational Research Consortium
- Therapeutic Advances in Childhood Leukemia (TACL) Consortium

# Our promise to you

Everything we do is centered around providing the highest level of cancer and blood disorders care to patients. Additionally, we offer services to our care partners. We promise:

## ACCESS TO SERVICES

- Pediatric hematologists/oncologists are available 24/7
- Phone consultations for hematology or oncology questions are available 24/7
- Same-day outpatient appointments are available as needed
- Same-day in-hospital consultations are available at both of Children's hospital locations

## TIMELY COMMUNICATION AND TEST RESULTS

- Regular phone updates are provided during diagnosis as well as throughout treatment and recovery
- Timely consultation notes are sent following outpatient visits

# Locations

## INPATIENT



**Children's – Minneapolis**  
2525 Chicago Avenue South  
Minneapolis, MN 55404



**Children's – St. Paul**  
345 North Smith Avenue  
St. Paul, MN 55102

## OUTPATIENT CLINICS

**Children's Specialty Center  
Cancer and Blood Disorders Clinic and  
the C.H. Robinson Infusion Center**  
2530 Chicago Avenue South, Suite 175  
Minneapolis, MN 55404

**Pediatric Short Stay & Infusion Unit at  
CentraCare Health Plaza**  
1900 CentraCare Circle  
St. Cloud, MN 56303

**Hudson Hospital and Clinics  
Infusion Center**  
405 Stageline Road  
Hudson, WI 54016

**Children's Physician Access**  
**24/7 assistance: referrals,  
consultations, admissions**

**612-343-2121**  
**866-755-2121**



**Children's Patient/Family Access**  
**Appointments, questions  
and more**

**612-813-5940**  
**888-811-5940**



[childrensMN.org](http://childrensMN.org)