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# Learn more

Go to [childrensMN.org/research](http://childrensMN.org/research) to:

- Watch the educational video about positive NBS results and the genetics of cystic fibrosis.
- Request Renee Temme, MS, CGC, genetic counselor at Children's to speak to your team about newborn screening for cystic fibrosis, CFTR-related metabolic syndrome and other CFTR-related disorders.
- Learn about other cystic fibrosis research at Children's.

## Children's Physician Access

24/7 assistance: referrals, consultations and admissions  
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# Research at Children's

Making a  
difference  
for kids  
with cystic  
fibrosis



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



## About the cystic fibrosis program

The cystic fibrosis (CF) program at Children's Hospitals and Clinics of Minnesota follows more than 150 patients. Led by a dedicated team with special training and expertise in treating children with cystic fibrosis, our outcomes rank us among the top 10 programs nationally in pulmonary function.

### At a glance

- Our pediatric cystic fibrosis program follows more than **150 patients**.
- We received Cystic Fibrosis Foundation designation as a **Therapeutic Development Network Center** in 2009.
- We continually rank among the **top CF centers** for efficiently enrolling patients in both treatment and observational research studies.
- Children's developed a confidential **cystic fibrosis Listserv** to help families stay connected with clinical and research program updates.

### Award winning

- Children's was recognized by the North American Cystic Fibrosis Conference with a Quality Care Award recognizing outstanding quality improvement processes and accomplishments for sustained commitment to quality improvement resulting in improved outcomes.
- Children's CF Medical Director, John McNamara, MD, received the Outstanding Partnership Award for our center's work with the Minnesota Chapter of the Cystic Fibrosis Foundation and the Angela Warner Friend to the Foundation Award.

## Cystic fibrosis research facts

Children's cystic fibrosis program diagnoses and treats children with all stages of CF. It is Children's mission to improve both the quality of care we provide and the overall quality of life for the CF patients we serve. We do this through ongoing clinical research.

### Cystic fibrosis clinical research investigators

Children's CF team is uniquely qualified. Most physicians are double-boarded in specialties such as pediatrics, pulmonology, neonatology and intensive care medicine. Eleven of our cystic fibrosis team members support research studies as principal investigators, subinvestigators or discipline-specific support staff.

### By the numbers

**#6** - In 2012, the Therapeutic Development Network Center ranked Children's #6 out of 77 centers for turnaround time from when a research study is activated to the time the first patient is enrolled.

**\$1.9 million** - The amount generated in funded cystic fibrosis studies, registries and capacity grants since 2009 at Children's.

### Current cystic fibrosis clinical research at Children's

Children's currently has **19 open protocols**

- 8 prospective treatment (1 pending review)
- 6 prospective observational
- 4 retrospective reviews
- 1 registry

Children's volume of CF research has grown significantly over the last few years. Learn about one of our CF studies...

## Studying quality improvement in genetic counseling following positive newborn screens for CF

A study led by Renee Temme, MS, CGC, genetic counselor at Children's, evaluated whether or not parental knowledge about the genetics of CF and their child's CF carrier status following genetic counseling improved when a short educational video was viewed after counseling.

### Background

Minnesota started screening all babies for CF on March 1, 2006. Diagnosing cystic fibrosis at an early age provides many benefits, including early initiation of treatment. Some carriers of CF are identified through the newborn screening (NBS) process. All infants with one or two cystic fibrosis transmembrane conductance regulator (CFTR) gene mutations identified have follow-up sweat chloride testing around one month of age.

Children's set out to improve parental understanding of the newborn screening results for CF by creating a short educational video that presents information about the newborn screening result, the sweat test, the genetics of CF, the child's CF carrier status, and the symptoms of CF. Children's researchers also assessed resources used by families before and after the appointment.

### Conclusion

The study findings reinforce the importance of genetic counseling and education for families with infants who screen positive for cystic fibrosis. The video increased parental understanding of the NBS results immediately following genetic counseling. Moreover, the knowledge was sustained for both video and non-video groups six weeks post-genetic counseling. Most parents reported they accessed resources available online about CF before coming in for follow-up testing. Therefore, the video is now available online for parents to view after learning of their child's positive NBS result and before follow-up testing. Children's research team is also presenting the results at the October 2013 North American Cystic Fibrosis Conference.



Renee Temme, MS, CGC, shown to the right, is a genetic counselor at Children's.