



Your child has been
diagnosed with CF...

Now what?

ROADMAP
OF CF

LIVE
BREATHE
INSPIRE



The Bonnell Foundation: Living with Cystic Fibrosis
www.roadmaptocf.org



Emily and Molly, the Bonnell's two beautiful daughters. When they were diagnosed with CF, Laura Bonnell made it her mission to raise awareness about the disease.

Mission Statement

To help educate parents and find a cure for Cystic Fibrosis, so that one day no CF parent will experience the pain and loss of losing a child to this disease.

Our Story

When I was 12 years old I knew I wanted to be a news reporter. I thoroughly enjoyed my television and radio career (and still am). I felt I was making a difference in peoples lives. I went jogging with President Clinton (until my nylons ran and he left me in the dust). I have met politicians (then Attorney General Janet Reno), rock stars (Ted Nugent, Joe Perry

and Mitch Ryder), national news correspondents and ABC News Anchor Peter Jennings. The list goes on, but truly the best stories I write and broadcast are about people trying to make a difference in the world.

Seventeen years ago, when Molly was born, my purpose in life became clear. Molly (and later Emily) were diagnosed with cystic fibrosis. We were shocked to learn they had CF. We had no idea we were carriers. Joe (my husband) had 7 siblings who didn't have children with CF. My mission in life is to raise awareness about CF.

Cystic Fibrosis is a genetic disease that causes chronic and fatal lung infections and interferes with digestion. A faulty gene causes the body to produce a thick, sticky mucus. The life expectancy for children born with CF in 2011 is 37 years. CF affects approximately 30,000 people in the United States. There is no cure. The Bonnell Foundation (BF) was launched, with their brand name, Roadmap to CF in July 2010. The BF is a web based organization designed to help parents, family members and caregivers of children living with cystic fibrosis.

What We Do

- Help parents find their way through the insurance maze.
- Connect families to CF information, resources and other CF parents.
- Provide volunteer opportunities.
- Speakers' bureau.
- Non-medical information for newly diagnosed families (for example, handling enzymes in school, getting a therapy vest for two kids, etc).
- Help you find answers to your CF questions.
- Provide medical scholarships (including lung transplants) and academic scholarships.
- Fund CF research.

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Purpose

The purpose of The Bonnell Foundation is to provide tools to navigate the difficulties of living with CF. We strive to connect families with resources through their CF journey. With our website, roadmap to CF baskets, medical and academic scholarships we hope to equip families with a roadmap to guide their way.





University of Michigan
C.S. Mott Children's Hospital



Hospitals

The University of Michigan C.S. Mott Children's Hospital

1500 E. Medical Center Drive
Ann Arbor, Michigan 48109
(734) 936-6267
med.umich.edu

Did you know...

- When hospitalized, CF kids at U of M Health System are always on 12th floor East of the new Mott Children's Hospital.
- Clinic (regular visits) are on the 6th floor of the new patient building.



The University of Michigan Health system is equipped both emotionally and medically to deal with children who have CF, and their parents. My greatest delight is the confidence that I see in parents and children as they become teens and "graduate" to adulthood. Maintaining good health is really complex and requires a lot of time and attention. When I hear parents call me and explain an illness or treatment, I smile because of the sophistication this takes. This kind of attention is what allows our kids to take International trips, play in competitive sports, attend college and remain as normal as possible in their every day lives. ””

Sue Critz, RN-C, MS, AE-C Clinical Staff Nurse, Pulmonary Division

““ I like U of M hospital, because the doctors and nurses understand my needs. They are always willing to answer all my questions and spend extra time with me. Plus there is a bonus, my favorite nurse is there. She makes me feel better. ””

Cody Child with CF

““ We are at The University of Michigan Health System for many reasons. Dr. Samya Nasr always has a wealth of information for us. She has news on the latest study and how it will impact the girls. The nurses are our life line, as well as the people who answer the phones for the clinic. If I have a question, or one of the girls is sick, they get back to me right away. The girls love the hospital too. We let them make the decisions they can, and the staff respects that. ””

Joe Father

““ After being at a different care center for 24 years, I was a bit uneasy and nervous to make the switch to U of M. The minute I walked into the U of M CF clinic and met the staff I was totally put at ease because of the kindness, dedication and love they exuberated. ””

Emily Adult with CF





Directions to U of M C.S. Mott Children's Hospital

From North of Ann Arbor

- Take US-23 south to exit 45.
- Merge onto M-14 W to exit 3.
- Turn left at Depot St.
- Turn left at Fuller Rd.
- Turn right at E Medical Center Dr.

From South of Ann Arbor

- Take US-23 north to exit 37B.
- Turn right at Glen Ave.
- Turn right at E Medical Center Dr.

From East of Ann Arbor

- Take I-94 west to exit 180B.
- Merge onto US-23 N to exit 37B.
- Turn right at Glen Ave.
- Turn right at E Medical Center Dr.

From West of Ann Arbor

- Take I-94 east to exit 172.
- Slight left at Jackson Rd.
- Turn left at Glen Ave.
- Turn right at E Medical Center Dr.

Did you know...

Patients and inpatient visitors can pay a lower parking fee by having their parking tickets stamped.

\$1 first hour

\$2 (daily maximum) per calendar day if length of visit is longer than one hour

50 cents per exit (for infusion clinic)

Outpatients can get their tickets stamped at the clinic where they are being treated. Inpatient visitors can get their tickets stamped on the floor of the patient they are visiting, at the floor nursing station or at the main information desk in the 2nd floor lobby of Mott Children's Hospital.

**Embrace Cystic Fibrosis by staying
ahead of it at all times - do not let
CF control you.**

Everyone's CF journey is different.





Children's Hospital of Michigan

DMC DETROIT MEDICAL CENTER



Children's Hospital of Michigan Specialty Center Detroit

3901 Beaubien Street
Detroit, Michigan 48201
(313) 745-5267
www.childrensdmc.org

Did you know...

- When your child is admitted to the hospital, you will choose two adult Family Partners. These are special people in your child's life. They may be parents. They may be grandparents, other relatives, or friends. You decide. Family Partners are not considered visitors at the Children's Hospital of Michigan. They are valuable members of the team.



We have an incredible team here at Children's Hospital of Michigan and will be there to support you and your family on your CF journey. ””

Deborah Hachey, RN, BSN, CPN Cystic Fibrosis Nurse Coordinator



Why Children's Hospital of Michigan? We can't imagine going anywhere else! Our first visit to Children's was when my daughter was three months old. Our daughter has been treated like she is the most important patient in the clinic or the hospital. The staff takes the time to ask her about little things like the picture she was coloring or a shirt she happened to wear that day. We greatly value the support and education that is offered. When we have questions, we are given answers professionally and in a timely manner. The information learned on "family nights" are relevant and helpful. Having been able to connect with other parents has made this road a little easier to travel. ””

Dena Mother



I was referred to Children's Hospital of Michigan by our pediatrician, he said it was the best in the area and he was right. Everyone at CHM treats my daughter with care and concern, in the clinic and in the hospital. Tess feels welcome to talk about who she is and what makes her happy, not just her disease. I ask a lot of questions and never feel rushed, the doctors and nurses treat us with patience and respect. All of the attention and care makes Tess feel welcome and safe. The excellent care the nurses and doctors provide have helped her remain healthy so I can feel confident we're giving her the best chance for a healthy future. ””

Helen Mother



Children's Hospital of Michigan is a friendly place – sort of Home away from Home – a place that makes me feel better. ””

14 year old girl diagnosed with CF at age 3



The CF clinic at Children's Hospital of Michigan is good, I like the snacks and not having to wait to long to be seen. ””

13 year old boy with CF

Jeffrey Sauger for The New York Times



(248) 860-3899



Directions to Children's Hospital of Michigan

From North of Detroit

- Take I-75 south to the Mack Avenue exit.
- Turn right on to Mack Avenue and go to the second traffic light, which is at Beaubien.
- Turn right onto Beaubien.
- Children's Hospital of Michigan will be on your left.

From South of Detroit

- Take I-75 north to the Mack Avenue exit.
- Turn left onto Mack Avenue and go to the third traffic light, which is at Beaubien.
- Turn right onto Beaubien.
- Children's Hospital of Michigan will be on your left.

From East of Detroit

- Take I-94 west to the southbound I-75 Freeway.
- Stay in the right lane once you are on I-75 south.
- Take the Mack Avenue exit off of I-75.
- Turn right onto Mack Avenue.
- Go to the second traffic light, which is at Beaubien.
- Turn right onto Beaubien.
- Children's Hospital of Michigan will be on your left.

From West of Detroit

- Take I-94 east to southbound I-75.
- Stay in the right lane once you are on I-75 south.
- Take the Mack Avenue exit off of I-75.
- Turn right onto Mack Avenue.
- Go to the second traffic light, which is at Beaubien.
- Turn right onto Beaubien.
- Children's Hospital of Michigan will be on your left.

Did you know...

Parking is \$2.50 per day

Valet is \$4.00 (if you have a handicap pass Valet is \$2.50)

If your child is hospitalized for more than 15 days you can request a free parking pass from the Social work department.

Thoughts on CF

"I should take lots of pictures..."

TRUE! It is always a good idea to take heaps of pictures of your child. Of course, CF does nothing to change that.

Other Hospitals

Women and Children's Center
Grand Rapids CF Center
(Pediatric)
Grand Rapids, Michigan
Appointments: (616) 391-2125

Hurley Children's Clinic
Hurley Children's Clinic is an outreach program of Children's Hospital of Michigan
Flint, Michigan
Appointments: (810) 257-9344

Kalamazoo Center for Medical Studies
(Pediatric)
Kalamazoo, Michigan
Appointments: (269) 337-6433

Michigan State University CF Center
Michigan State Specialty Clinic
(both Pediatric and Adult)
Lansing, Michigan
Appointments: (517) 364-5440

Thoughts on CF

"My child will die young..."

FALSE. The life expectancy of children born with CF in 2011 is 37 years, and medical advancements constantly continue to increase this expectancy and make it easier to live with this disease.



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Children's Special Health Care Services

CSHCS provides help to families of children who have chronic health problems or disabilities. Children must have a qualifying medical condition and be 20 years old or younger. Persons 21 years and older with Cystic Fibrosis or certain blood coagulation disorders may also qualify for services. They:

- Help pay for child's special medical care needs
- Help arrange for supplies and equipment
- Assist with referrals to community resources

CSHCS is located in the North Oakland Health Center at:

1200 North Telegraph
Bldg 34E
Pontiac, Michigan

For more information call
(248) 858-0056
(800) 758-9925

(ask for "Children's Special Health Care Services")

Thoughts on CF

"I can't have more children..."

FALSE. You have several options to consider including invitro fertilization where doctors can fertilize an egg that does not carry the CF gene.

Portraits of Cystic Fibrosis Calendar

The Portraits of Cystic Fibrosis calendar made its debut in 2003 and remains a beautiful tribute to the people who live their lives with CF. The Portraits of Cystic Fibrosis calendar is dedicated to everyone with CF fighting to stay healthy. We all have to do our part to help find a cure for cystic fibrosis, so that one day no CF parent will experience the pain and loss of losing a child to this disease.

Donations to purchase the Portraits of Cystic Fibrosis calendar through The Bonnell Foundation: Living with Cystic Fibrosis, help support CF families through research, with medical and academic scholarships and where medical coverage falls short.

The Portraits of cystic fibrosis calendars have cost \$15 since they began in 2003. The calendars are produced yearly and feature the black and white photographs of the inspirational people living with CF.

Each person writes an inspirational message on their page. For a calendar or to be featured in the calendar please write or email us:

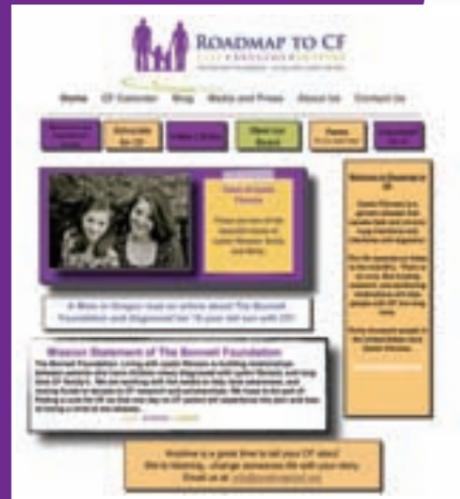
The Bonnell Foundation
P.O. Box 1215
Royal Oak, Michigan 48068
or
info@roadmaptocf.org





Goals of the Roadmap to CF website

- 1 www.roadmaptocf.org is a go to destination where CF parents can better navigate sources and support through a life of CF.
- 2 Provide scholarships and funding where needed such as CF research, where medical coverage falls short, student scholarships, and lung transplants.
- 3 Connect CF families to other CF families, provide mentorships, and volunteer opportunities thereby fostering a supportive community.



Become a Volunteer

There are many ways you can volunteer. We need your help. Please contact us at: info@roadmaptocf.org

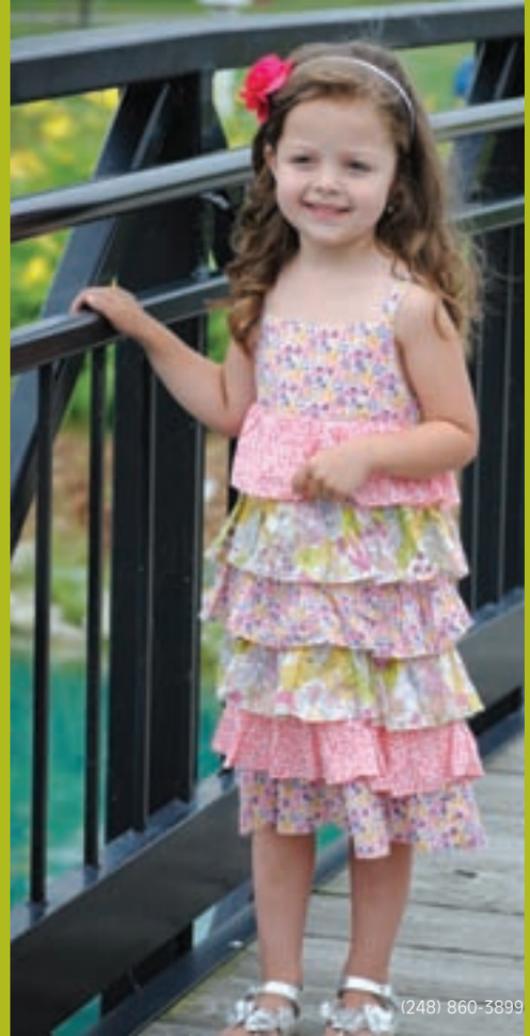
Fundraising Events

- For "the Love of Marge" – dinner & auction
 - Annual Bonnell Golf Classic
 - Margaret Carmona Golf Classic
 - Portraits of Cystic Fibrosis calendars
 - CF Reunion Jam
- *more to come...

Become a Sponsor/Investor

Investing in The Bonnell Foundation provides cystic fibrosis families with a roadmap to navigate through the challenges of this terminal disease. The Bonnell Foundation greatly appreciates any amount you can donate.

Platinum Level Sponsor	\$5,000 and up
Gold Level Sponsor	\$3,000
Silver Level Sponsor	\$1,500
Bronze Level Sponsor	\$500





Your child is an individual first and not defined by cystic fibrosis.

Bonnell Foundation Headquarters

P.O. Box 1215
Royal Oak, Michigan 48068
(248) 860-3899

info@roadmaptocf.org
www.roadmaptocf.org

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