



ADVOCACY
Toolkit



In 2011, the 111th Congress recognized a resolution naming December 1-7 Crohn’s & Colitis Awareness Week, an important step for increasing awareness about inflammatory bowel diseases. Help keep the success going by getting involved.

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Welcome to CCFA Advocacy! CCFA is pleased to provide this Toolkit, which contains important information about advocacy and additional helpful resources. This document will be of use to patients and their families, advocacy groups, and others with an interest in supporting the rights of inflammatory bowel diseases (IBD) patients. This toolkit will help ensure your voice is heard in Congress and promote legislative action for IBD patients and their families. Raising awareness about Crohn’s disease and ulcerative colitis is as easy as writing a letter or making a phone call to share your story. Here’s how to get started.

CONTENTS

About CCFA.....	2	Writing Your Representative a Letter or Email	6
CCFA’s Advocacy Committee.....	3	Calling Your Legislator.....	6
The Congressional Crohn’s and Colitis Caucus	4	Visiting Your Legislator’s Office in Washington, DC	8
Crohn’s & Colitis Awareness Week	4	Town Hall Meetings and Home Visits.....	8
The Lifecycle of a Bill.....	5	Social Media	10
Getting Started.....	6	Obtaining a Proclamation.....	11
Finding Your Representative.....	6	Restroom Access Act.....	13

OTHER HELPFUL RESOURCES

Sample Letter	7	Team Challenge.....	16
Talking Points for Meetings with Representatives	9	Camp Oasis	17
Sample Proclamation.....	12	Educational Resources	18
Take Steps	15	Toolkit Evaluation Form.....	20



About CCFA

The Crohn's & Colitis Foundation of America (CCFA) is the largest voluntary non-profit health organization dedicated to finding cures for IBD and improving the quality of life of those afflicted with Crohn's disease and ulcerative colitis. CCFA's mission is to cure Crohn's disease and ulcerative colitis, and to improve the quality of life of children and adults affected by these diseases.

The Foundation has played a key role in nearly every major breakthrough in IBD in the last 45 years. It was founded in 1967 by Irwin and Suzanne Rosenthal, William and Shelby Modell, and Henry Janowitz, M.D., with the goal of curing IBD. CCFA has invested more than \$169 million in research since its inception.

What is IBD?

Inflammatory bowel diseases (IBD), which include Crohn's disease and ulcerative colitis, affect as many as 1.4 million Americans, most of whom are diagnosed before age 30. These chronic, life-long conditions can be treated but not cured. IBD can significantly affect patients' quality of life and may have a high financial burden. By generating greater awareness of Crohn's disease and ulcerative colitis, CCFA believes that more progress can be made toward finding cures and reducing the significant impact of these diseases on individuals and the US healthcare system.

What We Do

Improving Quality of Life

CCFA is dedicated to improving the quality of life for those with inflammatory bowel diseases. We provide support services by phone, mail, or email and offer a free online community where

individuals can communicate with others who are also seeking to manage their condition. We also provide unbiased, accurate, and authoritative information in order to educate our community about living with Crohn's disease and ulcerative colitis, medication options, managing symptoms, and how to care for kids and teens with IBD.

Fund Research

Since its inception, CCFA has funded more than 1,100 grants. We invest our dollars wisely, funding the highest-quality IBD research anywhere in the world and implementing a peer-review process to ensure that only the most promising and relevant grant applications are funded.

Advocacy

CCFA encourages its advocacy members, volunteers, and friends to become actively involved in advancing our policy goals. We've already achieved great success in urging our legislators to implement responsible policies that transform the lives of those affected by Crohn's and colitis.

Raise Funds

CCFA deploys a multifaceted strategy to raise money and fund research into the causes of and treatments for Crohn's and colitis. More than 82 cents of every dollar raised goes directly toward mission-critical programs.

Local and regional fundraising activities are also conducted by the Foundation through our chapters. These include our signature events: [Team Challenge](#), an endurance training program, and [Take Steps](#), our national walk program.



CCFA's Advocacy Committee

Statement of Purpose

CCFA's National Advocacy Committee is made up of CCFA volunteers, medical professionals, and Board of Trustee members. The National Advocacy Committee develops positions on relevant issues, as well as recommends and implements strategies promoting the interests of the Crohn's and colitis community.

CCFA's Strategic Plan

Goal: To raise awareness, expand education, and increase support for research of inflammatory bowel diseases (IBD) through expanded local and national advocacy efforts.

Strategy I: Sustain Federal funding for IBD research.

Funding to the National Institutes of Health (NIH) is vital to IBD research. CCFA provides seed money to support worthy projects, but these projects need subsequent funding by NIH to reach their full potential.

Strategy II: Identify and partner with other societies and organizations to advance CCFA's advocacy goals and to achieve a strong voice with key constituents.

In the Restroom Access Act mini-toolkit on [page 13](#), you'll find more information about how advocates have partnered with other organizations with the same goals to get legislation passed. Chances are, people with other conditions would also benefit from IBD research, it's just a matter of finding them.

Strategy III: Develop a comprehensive branded advocacy program to reach new constituencies—a toolkit for advocate use!

Strategy IV: Provide resources and information on access to care issues to all CCFA constituents.

Look through our resources or contact your local chapter whenever you have a question. Can't find what you're looking for? Fill out the [Toolkit Evaluation](#) at the end of this toolkit and let us know. If you want to get involved and don't know how, drop us a line. We're here to help you with your advocacy goals!



Legislative Success

The Congressional Crohn's and Colitis Caucus

A congressional caucus is a group of legislators who work together to promote a common interest, such as a particular party's ideals or promoting awareness about a particular issue. In the case of the Crohn's and Colitis Caucus, it is a bipartisan interest group that is working to improve the lives of people with IBD. The Caucus was launched in May 2011 to promote awareness about IBD, funding for research, and increased access to healthcare for IBD patients. The Crohn's and Colitis Caucus is co-chaired by Congressmen Jim Moran (D-VA) and Ander Crenshaw (R-FL).

Crohn's & Colitis Awareness Week

In 2011, the U.S. Senate passed Senate Resolution 199 (S. Res. 199), "A resolution supporting the goals and ideals of Crohn's and Colitis Awareness Week, December 1-7." S. Res. 199 expresses appreciation to the family members and caregivers who support people in the United States living with Crohn's disease and ulcerative colitis. It also commends health care professionals who care for these patients and biomedical researchers who work to advance research aimed at developing new treatments.

How You Can Participate in Awareness Week:

- Write to your Representatives and encourage them to join the Crohn's and Colitis Caucus, www.capwiz.com/ccfa/home/.
- "Like" CCFA on Facebook (www.facebook.com/ccfab) and follow the Foundation on Twitter (www.twitter.com/ccfa).
- Change your Facebook status to: "I'm supporting Crohn's and Colitis Awareness Week and you should too! To learn more, go to www.online.ccfa.org/AwarenessWeek."
- Follow CCFA on Twitter all year long and use #CCFAawarenessweek.
- Change your profile picture to our logo during Awareness Week.
- Download our Awareness Week Poster, www.online.ccfa.org/AwarenessWeek
- Check out the Crohn's and Colitis Awareness Week press release.
- Visit www.ccfa.org to learn more about the diseases.

The Lifecycle of a Bill

A bill refers to a piece of legislation that is still in its draft form. After it is passed, it becomes a law and is enacted. Getting from the first draft of the bill to a law is a very long process and often takes many years and countless revisions to pass. The following flow chart shows how this process happens.





Getting Started

Why Advocate?

We advocate because it lets politicians know what issues are important to us. A politician's job is to make sure the interests of his or her constituents are represented in the laws that are enacted. That is why we have to educate legislators about the impact of IBD on Americans and that research and patient care are important to their constituents.

Finding Your Representative

First, look up your U.S. House Representative. You can do this in a few ways:

- By logging on to our representative finder (www.capwiz.com/ccfa/dbq/officials/) or the House of Representatives website (www.house.gov/representatives/)
- By calling our Information Resource Center at 888-MY-GUT-PAIN or 888-694-8872

Once you know who your representative is, you can choose to call, email, send a letter, or attend a town hall meeting to speak to him or her.

Writing Your Representative a Letter or Email

Legislators get thousands of emails and letters every day from constituents like you. It is one of the ways they find out what issues are important and relevant. There are a few things that are important to remember when writing to your legislator:

- Keep your letter short and to the point
- Your purpose for writing should be stated in the first paragraph

- When referring to a particular piece of legislation, identify it by number, (example: HR111)
- Focus on one issue per letter
- Use examples and your experiences to support your points
- Type your letter if possible

Calling Your Legislator

Calling is another great way to contact your legislator. If you don't know your district or don't have access to the Internet, call the U.S. Capitol Switchboard at 202-224-3121 and ask to be directed to your representative's office. Chances are you will not be able to talk directly with your legislator, but you will be able to talk to the aide in charge of health related issues. Introduce yourself and ask the aide to leave a message for your representative. A sample conversation would sound like this:

"Hello, my name is John Doe and I am one of the Representative's constituents. Please tell Representative XX that I would like her to join the Crohn's and Colitis Caucus. I am affected by IBD, as are 1.4 million Americans, and I know just how painful and debilitating gastrointestinal disorders can be."

You can share a personal story or talk more about why research and patient care is important to you but remember: keep it short and to the point.

The total annual direct and indirect costs for all patients with IBD in the United States in 2009 was \$2.6 billion.

Sample Letter

Here is a sample letter to Representative Norton from the District of Columbia:

The Honorable Eleanor Holmes Norton
2136 RHOB House Office Building
United States House of Representatives
Washington, DC 20515

Dear Representative Norton:

As a constituent and someone affected by inflammatory bowel diseases (IBD), I am writing to urge you to help make a difference in the lives of 1.4 million Americans living with Crohn's disease and ulcerative colitis.

Crohn's disease and ulcerative colitis (collectively known as IBD) are painful and debilitating disorders of the gastrointestinal tract that represent a leading cause of morbidity from digestive illness. We do not know their cause, their prevalence, or why the diseases vary significantly from patient to patient.

Congressmen Ander Crenshaw (R-FL) and Jim Moran (D-VA) have launched the Congressional Crohn's and Colitis Caucus. This caucus works to promote awareness of IBD, the need for expanded research at the National Institutes of Health and Centers for Disease Control and Prevention, and the importance of accessible insurance and disability for patients.

Please ask your staff to contact Nicole Golonka in Rep. Ander Crenshaw's office (Nicole.Golonka@mail.house.gov, 5-2501) or Marcia Knutson in Rep. Jim Moran's office (Marcia.Knutson@mail.house.gov, 5-4376) in order to join the caucus or request additional information.

Sincerely,
Jane Doe



Visiting Your Legislator

Visiting Your Legislator's Office in Washington, DC

Another way to have your voice be heard is by speaking with your representative in person. This method can be very effective because it gives you a chance to have a conversation with your representative. There are a few things you should consider before making a congressional visit:

- **Plan your visit carefully.** Know exactly which representative or member you need to speak to.
- **Make an appointment** with the Appointment Secretary/Scheduler. Explain your purpose and who you represent.
- **Be punctual and patient.** Representatives have a very crowded schedule and you have to be flexible. Your representative may be late or have to leave early.
- **Be prepared** with materials to support your position.
- **Paint the "big picture"** for the representative. Put your statements in terms of why they are in the best interest for your state/district.
- **Be responsive** and ready to answer questions. Your legislator may ask for additional information or materials. Make sure to send these promptly and always send a thank you letter reminding him/her of some of the main points from your meeting.

Town Hall Meetings and Home Visits

Not everyone can make it to Washington, D.C. to speak to their representative. That's why representatives are often open to visits or hold town hall meetings while they are at home. You can locate town hall meetings and home visits by:

- **Calling his or her office.** If you don't know your district simply call the U.S. Capitol Switchboard at 202-224-3121 and ask to be directed to your representative's office. There will be an aide that can assist you.
- **Checking his or her website** for when they plan to have town hall meetings. You can find your representative's website by entering his or her name into an online search engine and looking for the page with a house.gov ending in the web address (it is most often the first result).



Talking Points for Meetings with Representatives

- 1. Thank you** for taking the time to meet with me/us.
- As members of the Crohn's & Colitis Foundation of America, we are here today to **ask for your support** on several important legislative activities that give hope to patients and families struggling with inflammatory bowel diseases (IBD).
- Approximately **1.4 million Americans suffer from IBD**. Although the disease can strike anyone at any stage of life, it disproportionately impacts children and young adults. 30% of all patients are diagnosed in their childhood years.
- Briefly describe IBD and tell your **personal story** about living with the disease.
- See the **Advocacy Priorities** sheet in the back of this toolkit for the current **legislative actions** that we would like your support on.
- These legislative actions hold **great promise** for IBD patients and their families.
- Please support** these important measures.



More Ways to Reach Your Representative

Social Media

Social media is a great way to get your friends and family involved. It is vital that legislators see constituent support of these issues, so the more people who contact them, the better. Here's a sample status: "I just asked my Congressman to join the Crohn's and Colitis Caucus." You can also post a status or tweet to thank your legislator for co-sponsoring a bill or becoming a member of the Caucus.

After you contact your representative, share your experiences and encourage others to do the same.

- Donate your status to CCFA on Facebook or G-chat
- Tweet about the issues (don't forget to use our hashtag, #ccfaadvocacy)

- Add a blurb about contacting legislators in your e-mail signature
- Blog about it
- Set your profile picture to CCFA's logo for Crohn's and Colitis Awareness Week
- Pin CCFA's logo to your Pintrest

Need More Help?

If you need more help getting involved, contact CCFA. We can direct you to your representative, help you with what to say or write, or talk with you about the issues.

Connect with us via:

- Email: advocacy@ccfa.org
- Phone: 888-MY-GUT-PAIN or 888-694-8872
- Your local chapter. Visit www.ccfa.org for all chapter listings.



Obtaining a Proclamation

In 2011, Senate Resolution 199 was passed to support the goals and ideals of “Crohn’s and Colitis Awareness Week,” an important step for increasing public understanding of IBD. A proclamation can also dedicate a week in your city or state to IBD. It is a great way to increase awareness of IBD and gain media coverage about its importance. A lawmaker may take months to issue a proclamation, so patience and perseverance are important. Starting is easy:

1. Find the **contact information** of your mayor or governor’s office. Some may have a separate Proclamations Office where you can submit a request. You can find this on your county’s website, using an Internet search engine, or by calling 311.
2. **Write** a letter or email to your governor or mayor stating that you would like to request a proclamation. Some important things to include:
 - 1.4 million Americans are diagnosed with IBD, and 30,000 new cases are diagnosed each year
 - A personal story about your disease
 - Why it is important to raise awareness
 - Make your request clear: “We would like to make December 1st through December 7th IBD Awareness Week”

- A sample proclamation (see [page 12](#) for an example)
 - Send the letter at least two months in advance of the date you’re requesting
 - Support letters from legislators and other citizens
3. **Mail or email** your letter to your elected official.
 4. If you don’t get an answer within two weeks, **follow up** your letter or email with a phone call.
 5. If there is a vote on the proclamation, it is important to **be there** for it. Showing commitment makes a big difference.
 6. **Pick up your proclamation.** Most often, you will have to pick it up in person. You can also ask your elected official to present it to your group and get local news media to cover it.
 7. Write a **thank you** note to your elected official.
 8. If your proclamation does not get passed, don’t get angry and don’t give up! Submit your request again for the next year.
 9. **Let us know:** send a copy of your proclamation to CCFA, or call us at: 800-932-2423, or email us at: advocacy@ccfa.org.



Sample Proclamation

Whereas, inflammatory bowel diseases affect 1.4 million Americans and 70,000 new patients are diagnosed every year; and,

Whereas, inflammatory bowel diseases are debilitating conditions that affect patients' quality of life and can even be life-threatening; and,

Whereas, government support is needed to increase availability of medicines for inflammatory bowel diseases and for research towards cures; and,

Therefore, I ____ declare December 1st through December 7th IBD Awareness Week in the state of ____.



Restroom Access Act

Patients in many states are working for the passage of a Restroom Access Act. Fourteen states already have such an Act: Colorado, Connecticut, Illinois, Kentucky, Maryland, Massachusetts, Michigan, Minnesota, Ohio, Oregon, Tennessee, Texas, Washington, and Wisconsin. In general, Restroom Access Acts allow a person with an eligible health condition, such as Crohn's disease, ulcerative colitis, irritable bowel syndrome, an ostomy, or bladder disorder, to use an existing employee restroom in a retail establishment, whether or not the restroom is available to the general public. Before beginning, you should familiarize yourself with the "The Lifecycle of a Bill" flowchart on [page five](#). Although federal and state governments differ slightly (for example, the governor, not the president, signs a state bill) the basic flow of the legislation is the same.

Gather Your Team

No one passes a law on his or her own. Realizing that you will need support is a crucial first step. Your local CCFA chapter likely has had others express an interest in passing the Restroom Access Act in your state; if not, the chapter can notify members of the effort and solicit help.

- Work with your chapter to identify individuals who can help with the effort.
- Contact other organizations that help people who suffer from urinary or fecal incontinence, including cancer and urology associations as well as related medical societies.

Find a Legislative Leader

You will need at least one legislative "champion" to help get your legislation through your state's process. In deciding who to ask to sponsor the legislation, consider the following: (1) do you have a legislator from both political parties; (2) is there a member of your state's legislature that has inflammatory bowel disease or another condition that requires immediate bathroom access, or a family member with an eligible health condition? Your local CCFA chapter should know the answer to that question. A legislator with a personal connection will be your strongest advocate.

Helpful Hints from an Advocate

"My high school government teacher sold me on the idea that a good idea would become a law and it didn't matter who represented that idea. While that is the ideal, it's not the reality.

I was lucky in that my legislator and co-author of the legislation was bright and faithful to the cause.

Looking back, I probably should have had a Republican and a Democrat introduce the legislation together and gather as many co-signers as possible before introduction.

Knowing more about the political geography would have saved me from banging my head against too many walls and likely shortened the process."

(Continued on [page 14](#).)

(Continued from [page 13](#).)

“During the night of the lame duck session when Michigan’s bill was finally passed, my representative told the Senate Majority leader that I was so dedicated to this bill. The Senator, having received numerous e-mails from me, understood implicitly.

The bill passed four hours later. It is not a bad thing to have that reputation on such a night.”

.....
-Jill, Michigan

Gather Your Facts

There is little worse than going to a meeting with a legislator and not knowing what you are talking about, especially as it relates to the diseases, how they work, what symptoms they cause, and how they are treated.

So do yourself—and the legislator—a favor and work with the CCFA chapter in your area to gather important information about Crohn’s disease and ulcerative colitis prior to your meeting. Know what the diseases are and how they affect people. Know how many people in your state are affected and have some personal stories prepared to share. For more tips on contacting or meeting with your legislator, check out [pages 6-10](#).

Contact Legislators

Once you convince a legislator to take up the cause by introducing it in either the House or the Senate, follow up with the following steps:

- Write letters, make phone calls, and/or arrange a meeting with selected legislators or their aides.
- Organize a small group to attend the meeting.
- Prepare for the meeting. Decide who will speak for the group on certain points. Have each member write a letter that describes their story to leave behind with the legislator or their assistant. Bring copies of CCFA brochures that describe the disease and symptoms.
- Bring copies of legislation that has been passed in other states and be prepared to discuss the experience of other states in administering and enforcing the legislation.
- Ask about next steps and follow up actions.
- Be persistent.

When the Act is Introduced

Once your Act is introduced in your state’s legislature, it most likely will be assigned to a committee that will hold a hearing. There are steps you should take at this point. For example,

- Ask your local CCFA chapter to send out an email blast to solicit support. Provide a link to your legislator’s website and ask individuals to contact their legislators and urge them to co-sign the legislation. Focus particular attention on the members of the Committee to which the Act has been assigned.
- Prepare for opposition. Though not true in every state, the opposition to the Restroom Access Act has included chambers of commerce and retailers’ associations. Learn how to answer their opposition in a positive way. You may also want to contact the CCFA chapters in the states that already have enacted Restroom Access Acts and find out how they handled opposition.
- Involve the press. Ask your local chapter to send a press release regarding the bill’s introduction to media across the state.
- If possible, set aside a day to visit the lawmakers on the committee. Call and make appointments with the individuals through their staff. Keep comments short. At the end of the meetings, lobby for their commitment to vote for the legislation and ask them to push for a hearing and a vote in committee. Be sure to send thank you notes to the legislators for their time and commitment to the matter.
- Prepare your testimony. Your story is the most powerful tool you have.
- After the hearing, send out another round of thank you notes and include a pitch for their commitment in voting for the legislation. At the same time, ask your local chapter to send another email blast to inform the members of the hearing and to encourage members to call or write all legislators on the committee to let them know of the interest in the bill’s passage.

Don’t Give Up

If your act isn’t passed this legislative cycle, try again. Be persistent and work with CCFA to get these important bills passed in your state.



CCFA's Signature Programs

CCFA has several signature programs to help raise funds for the Foundation to fund research and programs that improve the quality of life for IBD patients. Over 82% of the money raised goes straight to mission-critical programs.

Take Steps

[Take Steps](#) for Crohn's & Colitis is CCFA's largest fundraising event. Participants raise funds and awareness throughout the year and come together to celebrate the steps that have been taken towards a cure. We walk because over 1.4 million American adults and children are affected by digestive diseases—one out of every 200! So many suffer in silence, but Take Steps is changing that by bringing this community together publicly and encouraging them to make noise and be heard.

Take Steps is now in all 50 US states, with over 160 walk sites scheduled this year alone! The money we raise through Take Steps helps support patient programs, enhances professional education efforts, and propels critical research for a cure. In the past five years alone, we succeeded in bringing together over 100,000 people and raised close to \$40 million to help further CCFA's mission.

Here Are Some Easy Things You Can Do For Take Steps:

- [Register](#) for a walk near you, form a friends and family team, corporate team with co-workers or walk as an individual.
- [Download](#) our new fundraising app—this will let all of your Facebook friends know you are raising money for an important cause, and give them the option to join your team.

- Place posters or brochures around your workplace and local neighborhood venues with your contact information. When people contact you, let them know about the walk and joining your team.
- Reach out to your internal network—neighbors, hairdresser, lawyer, etc.—and ask them to join your team. People who you do business with, have a relationship with, and know your story will have an interest in supporting you in this important cause!
- Place coin canisters in your child's school or other local businesses. Those coins add up and get people talking! Contact your local chapter to order canisters.
- Place our banners (available on the [Take Steps](#) website) on your blog, Facebook® page, and on emails to friends to help us spread our message.

Get inspired

Last year, Team Gestalt raised over \$40,000. Team Captain Norman Shub, had this to say about why he fundraises and his Take Steps experience:

"We are very proud to be the top team because we helped and will continue to help CCFA! What was a shock to me was my reaction to the walk. By the time I was called up to the stage to be recognized for my efforts I was so choked up I could not speak.

We love that so many came out to support these amazing families of all ages!"



Team Challenge

[Team Challenge](#) is the Crohn's & Colitis Foundation of America's endurance training and fundraising program. With Team Challenge, you'll find new strength inside yourself, and help find cures for Crohn's disease and ulcerative colitis—two painful, debilitating, and seldom-discussed digestive diseases.

With our [Half Marathon](#) and [Triathlon](#) Training Programs, you'll train for a rewarding and exciting endurance event at one of our great destination races while raising vital funds for research into these diseases. Funds raised will help make new treatments possible and fuel the search for cures.



Here's What Team Challenge Provides:

- Personalized fitness training by an experienced coach for an entire season
- Expenses-paid weekend away to a great destination race
- A supportive team to train with each week
- Training clinics and helpful tips on topics like nutrition, hydration, injury prevention and shoe fit

- Team Manager, a dedicated CCFA staff person who coordinates team events, guides you through fundraising, and will encourage you all season!
- Mentor, a past participant of Team Challenge who can show you the ropes and be your personal fundraising coach
- Team uniform including a training shirt and race day singlet

CCFA is an amazing organization that radiates with a positive energy unlike any other I have experienced. Over the months of training I found that I was actually able to run this distance (which I really didn't think was possible).

I met amazing people and formed wonderful friendships. It was truly a life changing experience and I'm excited to continue to be involved with such a worthwhile organization that has become important to me.

.....
Frankie, New York



Camp Oasis

Dealing with IBD as a child is even more challenging. That is why CCFA proudly established [Camp Oasis](#) over a decade ago. This co-ed, residential camp program enriches the lives of children with Crohn's disease and ulcerative colitis by providing them with a safe and supportive camp community.

A Life Changing Experience

Since all of the campers (and most of the adults) at Camp Oasis are living with IBD, our understanding team allows them to:

- See that they are not alone
- Try things they never imagined
- Create friendships with people who truly understand them
- Listen to and share their IBD stories
- Gain confidence
- Heal and build their spirits

Outstanding Medical Care

Our volunteer physicians, nurses, and other health care professionals are available for 24-hour care, and work to ensure campers follow regimens prescribed by their doctors back home.

A Quality Program

Camp Oasis was built upon the highest standards of care, and offers activities that appeal to every taste:

- Visual and performing arts
- Land and water sports
- High ropes and other outdoor adventures
- Leadership development (for our oldest participants)



Our schedule also allows children plenty of time to relax, get to know one another, and share the best medicine of all—laughter!

Dedicated Staff

CCFA carefully screens and trains all volunteer staff—most of whom are adults also living with IBD. These responsible and empathetic individuals work hard to ensure that every camper feels safe, comfortable, and has the time of their lives.

You can find a camp near you on our website, ccfa.org, under the "[Get Involved](#)" section.



Educational Resources

As the nation's leading source of information for Crohn's and colitis patients and healthcare professionals, CCFA provides an extensive collection of resources.

With so many valuable resources covering a range of topics, we make it easy to find the content you need. You can search our website by keyword, disease, topic, audience, page type, posting date, and even by language at ccfa.org, under the "[Living with Crohn's and Colitis](#)" section. If you would like printed brochures mailed to you, fill out our [brochure order form](#) online. CCFA also offers webcasts throughout the year on various topics, and offers other educational websites such as "I'll Be Determined" (ibdetermined.org). You can also contact the Information Resource Center at 888-MY-GUT-PAIN to learn more about our resources.

Talking to a CCFA Specialist

While our educational resources contain almost everything you need to know about Crohn's disease and ulcerative colitis, there are some things that you'll want to discuss with a Crohn's and colitis information specialist.

Whether you're looking for a specific resource, referrals to other organizations, or answers to questions you can't find anywhere else, you can speak with our helpful specialists at CCFA's Information Resource Center (IRC).

Contact Us:

- By telephone at 888-MY-GUT-PAIN (888-694-8872) Monday thru Friday, 9:00 am to 5:00 pm EST
- By email at info@ccfa.org
- Via live chat on our website, ccfa.org
- By submitting a [contact specialist form](#) on our website
- Writing a letter to CCFA: 386 Park Ave South, 17th floor, New York, NY 10016, Attn: Advocacy

Support Groups

There are hundreds of CCFA support groups for people with Crohn's disease and ulcerative colitis throughout the country. Each year, CCFA's local chapters hold more than 300 support groups, where patients and family members can connect with others living with these diseases nationwide.

Crohn's and colitis support group meetings are often intimate gatherings where patients and their loved ones can share their stories, seek emotional support, find answers to their questions, and connect with a community that shares their challenges.

In addition to these focused sessions, support groups often organize informal, social events like picnics and luncheons, community volunteer days, informational workshops, family outings, and attend gala events. Find a support group by contacting your local chapter or, if you don't know your chapter, the IRC can direct you. You can also join our online support group program on the CCFA Community site (www.ccfacommunity.org).

Let Us Know About Your Success!

We're always trying to improve our advocacy program and we also want to know about your projects. Let us know what you've done, who you've met with, and what we can do to help. Please fill out the form below and mail it to us. Feel free to add in any press releases, photographs, copies of proclamations, or any other documents you'd like to share. Note: Photos sent may be used on our website and in other publications. By sending us your photos, you are granting permission for their use.

NAME

ADDRESS

CITY

STATE ZIP

PHONE

EMAIL

CHAPTER

Did you speak with any legislators or other elected officials? Yes No

NAME

CONGRESSIONAL DISTRICT

PHONE OR EMAIL

How did it go?

Did you get any media involvement? (We would love to have a copy of any articles or videos!)

Toolkit Evaluation Form

NAME

ADDRESS

CITY

STATE ZIP

PHONE

EMAIL

CHAPTER

Why did you get involved in CCFA advocacy?

Were there any questions this toolkit didn't answer for you?

Is there any way that CCFA can help? (Programs, activities, additional information?)

Anything else you'd like us to know:



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