

CEDNA - The survey

as part of a study to improve the care of children and adolescents with inflammatory bowel disease (IBD).



VERSION IBD PATIENTS - for children and adolescents with IBD from 12 to 17 years

For **ease of reading**, the masculine, feminine, and various forms of the language are used interchangeably. All personal terms apply equally to all genders.

This survey is only for children and adolescents with inflammatory bowel disease (IBD). We ask that you complete the questionnaire without assistance if you are between the ages of 12 and 17 and have IBD.

You can also **complete** the **CEDNA online**. See the information on the last page.

First, we will ask you to enter your own **questionnaire code**, because the survey is **anonymous**, which means that no one can find out that you have filled it out. With the help of the code it is possible to filter out duplicate questionnaires in the scientific analysis.

Please enter your **code** here following the instructions:

	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
	↑	↑	↑	↑	
First letter of first name of your mother			First letter of your place of residence	First two digits of your birthday (e.g. 4=04; 15=15)	
	Last letter of your first name				

Information about your disease

01. What IBD has your doctor diagnosed?

- Crohn's disease
- Ulcerative colitis
- Unclassified IBD

02. What concomitant diseases have you been diagnosed with?

(Please check more than one box if applicable)

- Primary Sclerosing Cholangitis (PSC)
- Skin diseases (erythema nodosum, pyoderma gangraenosum)
- Eye diseases (e.g. uveitis, iridocyclitis)
- Gall and kidney stones
- Thrombosis
- Inflammatory joint disease (e.g. rheumatism, idiopathic arthritis)
- Psychological disorders (e.g. depression, anxiety disorder)
- Other:
- None
- I do not know

03. How long have you been diagnosed with IBD?

- Less than 1 year
- 1 - 2 years
- 3 - 4 years
- 5 - 6 years
- Longer than 6 years

04. In the last 12 months, who was your main source of medical care for your IBD? (Main contact person)

- No main contact
- Primary care physician
- Pediatrician
- Pediatric gastroenterologist
- Adult gastroenterologist
- Other, specifically:

05. The course of IBD is usually intermittent. Phases of no symptoms or with minor symptoms (resting phase, remission) alternate with phases of severe symptoms (acute relapses). Which phase of the disease are you currently in?

- Diagnostic phase
- Resting phase/Remission
- Relapse phase
- I do not know

Medical and psychological care

06. If you have a physical problem related to your IBD, can you contact someone who can give you the support you need?

- Yes, always → Go to question 07
- Now and then → Go to question 07
- Rather not → Go to question 08

07. Who do you see if you have a physical problem related to your IBD? (Please check more than one box if necessary).

- Doctor
- Parents and family
- Friends
- Other, name:

08. If you have a mental or emotional problem related to your IBD, can you contact someone who can give you the support you need?

- Yes, always → Go to question 09
- Now and then → Go to question 09
- Rather not → Go to question 10

09. Who can you turn to if you have a mental or emotional problem related to your IBD? (Please check more than one box if necessary).

- Doctor
- Parents and family
- Friends
- Other, name:

10. Overall, are you satisfied with the medical care you receive for your IBD?

- Yes
- No

Managing chronic inflammatory bowel disease

11. You probably use different ways to manage your IBD. Which of the following methods do you use? (Think about the past three months)

	Yes	No
Talking about IBD with other people who have it		
Talking about IBD to family and/or friends		
Talking about IBD to your doctor		

Getting together with friends
Participating in hobbies
Doing relaxation exercises (yoga, autogenic training, etc.)
Taking care of yourself physically
Exercise and be physically active
Pay special attention to your diet
Get psychological support
Participate in support group activities
Other, specifically:

12. How do you feel when you think about your IBD?

	Yes	No
I am afraid		
I am ashamed		
I am insecure		
I am nervous		
I am sad		
I am calm		
I am helpless		
I am exhausted		
I have no more courage		
I feel lonely		
I feel overwhelmed		
I feel abandoned		
I think everything will be okay		

13. Have you been able to deal with your feelings about your IBD in the last three months?

- Not at all
- Only a little
- Most of the time
- Totally

How to get / share information

The following questions are designed to help us understand, how and where you get information about IBD. What are your ideas and wishes for finding and sharing information about IBD?

14. Do you feel adequately educated and informed?

- Not at all
- Only a little
- Mostly
- Totally

15. There is a variety of topics related to CED. On which topic do you feel well informed and where would you like to know more?

	I feel good informed about it		I would like to know even more about it	
	Yes	No	Yes	No
IBD in general				
Causes				
Drug treatment options				
Surgical treatment options				
Side effects of medications				
Complications in the progressive course of the disease				
Concomitant diseases				
Prognosis				
Preventive health measures (e.g. cancer screening, smoking cessation)				
Complementary medicine (e.g. homeopathy)				
Vaccinations				
Nutrition				
Coping with psychological stress and stress management				
Psychotherapy				
Transition to adult medicine (transition)				
Sexuality issues				
Social legal issues (employment promotion, health insurance, rehabilitation, disability law, pension insurance)				
School and education (e. g. compensation for disadvantages, possibility to go to the toilet at any time, information at school)				
Patient organizations & self-help groups				
Travel abroad with IBD				
Other, specifically:				

16. IBD can present many challenges. Therefore, non-physician professionals and facilities are also involved in the care. Which of the following treatment or counseling services do you use or have used? (Please check more than one box if applicable)

- Nutrition counseling
- Genetic counseling
- Family counseling
- Sexual counseling
- Physical therapy
- Occupational therapy
- Psychological help/support
- Stress management services (e.g. relaxation training, autogenic training)
- Outpatient nursing services, home help
- Support groups
- Advice from health or long-term care insurance
- Advice from pension insurance (e.g. rehab)
- Events that provide information about the disease (e.g. attendance of a seminar)

- Transition programs (e.g. Berlin Transition Program)
- Other, specifically:
- I do not or have not received any treatment or counseling

17. There are a variety of sources where you can find information about your IBD. Please indicate whether you find the following sources of information sources trustworthy and whether you have ever read about them.

	I find this source of information about IBD trustworthy		I have already read about the source of information on IBD	
	YES	NO	YES	NO
Doctors				
Pharmacists				
Medical societies				
Pharmaceutical industry				
Health insurance companies				
Non-medical practitioners				
Nutritionists				
Psychologists				
Psychotherapists				
Transition programs				
Other patients				
Patient associations (e.g. DCCV)				
Support groups				
Family, friends, peers				
Specific Internet forums, chat rooms				
Internet in general				
Television, consumer programs				
Scientific journals, textbooks				
Politics				
Other, specifically:				

18. How would you like to receive information about IBD? (Please check more than one box if applicable)

Printed information media

- Brochures and flyers
- Age-appropriate books for children and teens
- Professional journals and reference books
- Other, specifically:

Information events

- Lectures
- Conferences
- Other, specifically:

Online information

- Internet sites
- Patient counseling services
- Educational films
- Regular newsletters
- YouTube channel
- Blogs
- Apps
- Other, specifically:

Online communication platforms

- Forums for patients and/or parents
- Chats
- Apps
- Other, specifically:

Informational seminars

- One-day workshops
- Weekend seminar with overnight stay
- Weekend seminar without lodging
- Other, specifically:

19. Who should give you the information about IBD? (Please check all that apply)

- Adult specialists (gastroenterologists)
- Pediatric gastroenterologists
- Nurses
- Psychologists
- Current research scientists
- Nutritionists
- Sports specialists
- Social workers
- Experiential and music educators
- Patient associations
- Support group representatives
- Affected families
- Affected adolescents
- Lawyers
- Representatives of consumer protection/help centers
- Health insurance companies
- Others, specifically:

20. Now we are talking about information sharing opportunities. Would you attend one of the following? How many people should participate?

	Yes	No	2-5	6-10	11-15	>15
Group meeting of parents of affected children						
Group meeting of affected children and teenagers						
Group meetings of parents with their affected children						
Family weekends for affected children, parents and siblings						
Online communication platforms (e.g. forums, chats)						

Survey Statistics

In order to statistically analyze this survey, we need some information about you.

21. I am ...

- Male
- Female
- Divers

22. I am.....years old

23. I live ...

- With my biological parents
- With my mother and partner
- With my father and partner
- With my mother
- With my father
- With my grandparents or other relatives
- With my foster/adoptive parents
- In my own home
- In an institute
- In a group home
- Other, specifically:

24. I have ...

- No siblings
- 1-2 siblings
- 3 or more siblings

25. In which region do you live?

- Baden-Wuerttemberg

- Bavaria
- Berlin
- Brandenburg
- Bremen
- Hamburg
- Hesse
- Mecklenburg-Western Pomerania
- Lower Saxony
- North Rhine-Westphalia
- Rhineland-Palatinate
- Saarland
- Saxony
- Saxony-Anhalt
- Schleswig-Holstein
- Thuringia

26. I live in a ...

- Large city (with more than 500,000 inhabitants)
- Large city (with 100,000 to 500,000 inhabitants)
- Medium city (with 20,000 to 100,000 inhabitants)
- Small town (with 5,000 to 20,000 inhabitants)
- Rural community (with less than 5,000 inhabitants)

27. I currently attend ...

- An elementary school
- A junior high school
- A Secondary School/high school/comprehensive School
- A College
- No longer school

28. After school I would like to ... / I am currently doing ...

- Start an apprenticeship or vocational training
- Study at a university or a technical college
- Do voluntary service
- Do military service
- Doing nothing
- Other, specifically:

Study director: Prof. Dr. med. Jan de Laffolie

University Children's Hospital, Department of General Pediatrics and Neonatology, University Giessen, Giessen, Hesse, Germany

CEDNA - The survey

as part of a study to improve the care of children and adolescents with inflammatory bowel disease (IBD).



VERSION PARENTS - for parents of children and adolescents with IBD from 0 to 17 years

For **ease of reading**, the masculine, feminine, and various forms of the language are used interchangeably. All personal terms apply equally to all genders.

This survey is only for parents of children with inflammatory bowel disease (IBD) between the ages of 0 to 17. If you are a parent with multiple children with IBD, we ask that you complete a questionnaire for each child.

You can also **fill out CEDNA online**. See the info on the last page.

First, we will ask you to enter your own **questionnaire code**, because the survey is **anonymous**, which means that no one can find out that you have filled it out. With the help of the code it is possible to filter out duplicate questionnaires in the scientific analysis.

Please enter your **code** here following the instructions:

↑
First letter of the first name
of the patient's mother

↑
Last letter of the first
name of the patient

↑

First letter of the patient's place of residence

↑
First two digits of the birthday of the
patient (e.g. 4 =04; 15=15)

General questions about yourself

01. How are you related to the IBD patient?

- Mother
- Father
- Other, name:

02. Have you been diagnosed with IBD?

- Yes
- No

Information about your child's illness

03. Which IBD has your child currently been diagnosed with by a doctor?

- Crohn's disease
- Ulcerative colitis
- Unclassified IBD

04. Which concomitant diseases have been diagnosed in your child? (multiple answers possible)

- Primary Sclerosing Cholangitis (PSC)
- Skin diseases (erythema nodosum, pyoderma gangraenosum)
- Eye diseases (e.g. uveitis, iridocyclitis)
- Gall and kidney stones
- Thrombosis
- Inflammatory joint diseases (e.g. rheumatism, idiopathic arthritis)
- Mental disorders (e.g. depression, anxiety disorder)
- Other, namely:
- None
- I do not know

05. Please enter your child's age.

My child is..... years old.

06. Please indicate your child's gender.

- Male
- Female
- Diverse

07. How long has your child been diagnosed with IBD?

- Less than 1 year
- 1 - 2 years
- 3 - 4 years
- 5 - 6 years
- More than 6 years

08. In the past 12 months, who was your child's primary health care provider regarding IBD? (Main contact person)

- No primary contact
- Primary care physician
- Pediatrician
- Pediatric gastroenterologist
- Adult Gastroenterologist
- Other, specifically:

09. Looking at the course of your child's disease which of the following patterns of progression do you think is most likely to apply to your child?

- After a few episodes of disease, there was a period of remission. This has continued to the present day
- There are repeated episodes of the disease, which are interrupted by resting phases
- Disease is constantly active, the symptoms vary in severity
- Disease becomes more active, the symptoms increase in severity

10. The course of IBD is usually intermittent. Periods of no or minor symptoms (resting phase/remission) alternate with periods of severe symptoms (acute symptoms / acute relapses). What phase of the disease is your child currently in?

- Diagnosis phase
- Resting phase/remission
- Relapse phase
- I do not know

Medical and psychological care

11. If your child has a physical problem related to his or her IBD, can your child contact get the help he or she needs?

- Yes, always → Go to question 12
- Now and then → Go to question 12
- Rather not → Go to question 13

12. Who can your child talk to about a physical problem related to his or her IBD? (Multiple answers possible)

- Doctor
- Parents and family
- Friends
- Other, specifically:

13. If your child has a mental/emotional problem related to his or her IBD: Can your child talk to someone who can give him/her the support he/she needs?

- Yes, always → Go to question 14.
- Sometimes → Go to question 14
- Rather not → Go to question 15

14. Who can your child turn to for help with a mental or emotional problem in connection with his or her IBD? (Multiple answers possible)

- Doctor
- Parents and family
- Friends
- Other, specifically:

15. Do you have a pediatric gastroenterologist caring for your child?

- Yes → Go to question 16
- No → Go to question 18

16. How far do you travel to see a specialist and/or go to a specialty clinic where your child receives medical care?

- Less than 30 minutes
- 30-60 minutes
- More than 60 minutes

17. How many pediatric gastroenterologists and clinics specializing in children with IBD do you know of in your area (approx. 100 km away)?

- None
- 1
- 2-5
- More than 5

18. Are you generally satisfied with the medical care your child receives for IBD?

- Not at all
- Only a little
- Mostly
- Very satisfied

19. Has your child ever been denied health insurance coverage because of IBD?

- Yes, specifically:
- No

20. Are you generally satisfied with the your child's health insurance coverage for IBD?

- Yes
- No

Managing inflammatory bowel disease

We are interested in your child's treatment and management of inflammatory bowel disease. Please answer the following questions in relation to your child's current phase of the disease (phase of diagnosis, phase of acute relapse, phase of remission) of your child.

21. In the past three months, how often has your child used any of the following ways to cope with his or her own disease?

	never	rarely	regularly	often
Talking about IBD with others				
Talking about IBD to family and/or friends				
Talking about IBD with your doctor				
Getting together with friends				
Doing hobbies				
Doing relaxation exercises (yoga, autogenic training, etc.)				
Taking care of yourself physically				
Exercise and be physically active				
Pay special attention to the diet				
Get psychological support				
Participate in support group activities				
Other, specifically:				

22. During the current phase of your child's disease, how often have you felt the following emotions?

	Yes	No

Anxiety		
Shame		
Uncertainty		
Nervousness		
Depressed mood		
Serenity		
Confidence		
Helplessness		
Excessive demands		
Fatigue		
Discouragement		
Loneliness		
Being left alone		
Feeling guilty		
Being overprotective		
Fear for your child's future		

23. In the last three months, have you generally been able to cope with your feelings about your child's IBD?

- Not at all
- Only a little
- Most of the time
- Totally

How and where to find information

The following questions are designed to help us understand how and where you find information about your child's disease. What are your ideas and wishes for finding and sharing information about IBD?

24. Do you feel adequately educated and informed about IBD?

- Not at all
- Only a little
- Mostly
- Totally

25. There are many topics related to IBD. Please indicate below how well informed you feel about each topic and if you would like to learn more.

I feel well informed on ...	Not at all	Only a little	Mostly	Completely	I would like to know more
IBD in general					
Causes of IBD					
Drug treatment options					
Surgical treatment options					

Side effects of medications
Complications in the progressive course of the disease
Concomitant diseases
Prognosis
Measures for preventive health care (e.g. cancer screening, smoking cessation)
Complementary medicine (e.g. homeopathy)
Vaccinations
Nutrition
Dealing with mental stress and stress management
Psychotherapy
Transition to adult medicine (transition)
Sexuality issues
Family Planning
Social and legal issues (Employment assistance, health insurance, rehabilitation, law for the severely disabled, pension insurance)
School and education (e.g. compensation for disadvantages, possibility to go to the toilet at any time, information at school)
Patient organizations
Support groups
Traveling abroad with IBD
Other, specifically:

26. Please indicate which of the following treatment or counseling services you use or have used regarding your child's IBD. (Multiple answers possible)

- Nutritional counseling
- Genetic counseling
- Counseling about having children
- Family counseling
- Marriage counseling
- Sexual counseling
- Physiotherapy
- Ergotherapy
- Psychological help/support
- Stress management services (e.g. relaxation training, autogenic training)
- Outpatient nursing services, home help
- Support groups
- Advice from health or long-term care insurance
- Advice from pension insurance (e.g. rehab)
- Event that provide information about the disease (e.g. attending a seminar)
- Transition programs (e.g. Berlin Transition Program)

- Other, specifically:
- I do not use or have not used any treatment or counseling services.

27. Please indicate which of the following treatment or counselling services your child is using or has used in relation to his or her IBD. (Multiple answers possible)

- Nutrition counseling
- Genetic counseling
- Family counseling
- Sexual counseling
- Physical therapy
- Occupational therapy
- Psychological help/support
- Stress management services (e.g. relaxation training, autogenic training)
- Outpatient nursing services, home help
- Support groups
- Advice from health or long-term care insurance
- Advice from pension insurance (e.g. rehab)
- Events that provide information about the disease (e.g. attendance of a seminar)
- Transition programs (e.g. Berlin Transition Program)Other, specifically:
- My child does not use or did not use any treatment or counselling services.

28. Please indicate how trustworthy you consider the following sources of information regarding IBD and whether you are aware of the source?

	not at all	only a little	mostly	very much	I inform me about this source	
					Yes	No
Doctors						
Pharmacists						
Medical societies						
Pharmaceutical industry						
Health insurance companies						
Non-medical practitioners						
Nutritionists						
Psychologists						
Psychotherapists						
Transition programs						
Other patients						
Patient associations (e.g. DCCV)						
Support groups						
Family, friends, peers						
Specific Internet forums, chat rooms						
Internet in general						
Television, consumer programs						
Scientific journals, textbooks						
Politics						

29. How would you like to receive information about IBD? (Multiple answers are possible)

Printed information media

- Brochures and flyers
- Age-appropriate books for children and teens
- Professional journals and reference books
- Other, specifically:

Information events

- Lectures
- Conferences
- Other, specifically:

Online information

- Internet sites
- Patient counseling services
- Educational films
- Regular newsletters
- YouTube channel
- Blogs
- Apps
- Other, specifically:

Online communication platforms

- Forums for patients and/or parents
- Chats
- Apps
- Other, specifically:

Informational seminars

- One-day workshops
- Weekend seminar with overnight stay
- Weekend seminar without lodging
- Other, specifically:

30. Who should provide you with information about IBD? (Multiple answers possible)

- Adult specialists (gastroenterologists)
- Pediatric gastroenterologists
- Nurses
- Psychologists
- Current research scientists

- Nutritionists
- Sports specialists
- Social workers
- Experiential and music educators
- Patient associations
- Support group representatives
- Affected families
- Affected adolescents
- Lawyers
- Representatives of consumer protection/help centers
- Health insurance companies
- Others, specifically:

31. In the course of the disease there are different wishes and needs. The following list contains different topics. Please estimate which topic you would have been most interested in at the respective times of the IBD.

I would like information on ...	at the time of diagnosis	in the first year	in the further course	I do not need any information
IBD in general				
Causes				
Drug treatment options				
Surgical treatment options				
Side effects of medications				
Complications in the course of the disease				
Concomitant diseases				
Prognosis				
Preventive health measures (e.g. cancer screening, smoking cessation)				
Complementary medicine (e.g. homeopathy)				
Vaccinations				
Nutrition				
Coping with psychological stress and stress management				
Psychotherapy				
Transition to adult medicine (transition)				
Sexuality issues				
Family planning				
Social and legal issues (e.g. employment promotion, health insurance, rehabilitation, pension insurance)				
School and education (e.g. compensation for disadvantages, possibility to visit the toilet at any time, information at school)				

Patient organizations and self-help groups
Disease documentation (e.g. via IBD app)
Travel abroad
Other, specifically:

32. Now we are talking about information sharing opportunities. Would you attend one of the following? How many people should participate?

	Yes	No	2-5	6-10	11-15	>15
Group meeting of parents of affected children						
Group meeting of affected children and teenagers						
Group meetings of parents with their affected children						
Family weekends for affected children, parents and siblings						
Online communication platforms (e.g. forums, chats)						

Survey Statistics

In order to statistically analyze this survey, we would like to ask you to provide some information about yourself:

33. Please indicate your age.

- Younger than 20 years
- 20-30 years
- 31-40 years
- 41-60 years
- Older than 60 years

34. In which family environment does your child live?

- In a family with two parents
- With a single mother or father
- Other, specifically:

35. How many siblings does your child have?

- No siblings
- 1-2 siblings
- 3 or more siblings

36. In which region do you live?

- Baden-Wuerttemberg
- Bavaria
- Berlin
- Brandenburg
- Bremen
- Hamburg
- Hesse
- Mecklenburg-Western Pomerania
- Lower Saxony
- North Rhine-Westphalia
- Rhineland-Palatinate
- Saarland
- Saxony
- Saxony-Anhalt
- Schleswig-Holstein
- Thuringia

37. What is the size of the city/town your child lives in?

- Large city (with more than 500,000 inhabitants)
- Large city (with 100,000 to 500,000 inhabitants)
- Medium-sized city (with 20,000 to 100,000 inhabitants)
- Small town (with 5,000 to 20,000 inhabitants)
- Rural community (with less than 5,000 inhabitants)

38. What is your highest school-leaving qualification?

- No general school-leaving certificate or no school leaving certificate yet
- Secondary school leaving certificate
- Graduation from polytechnic secondary school
- Secondary school certificate or equivalent
- Grammar school

39. What is your highest level of education?

- No vocational qualification or still in vocational training
- Apprenticeship or dual vocational training
- Polytechnic degree (bachelor and/or master degree)
- University degree (bachelor and/or master and/or doctorate)

40. Is your child's medical information already included in a IBD patient registry?

- Yes
- No
- I do not know

41. Which of the following medical and patient associations are you familiar with?

- German Crohn's Disease / Ulcerative Colitis Association (DCCV e.V.)
- Society for Pediatric Gastroenterology and Nutrition (GPGE e.V.)
- Network for Children (KNW e.V.)
- German Society for Nutrition (DGE e.V.)
- German Self-Help Association for people with stoma and their relatives (ILCO e.V.)
- Competence Network for Bowel Diseases
- Transition Program (e.g. Berliner Transition Program)
- Others, specifically:

Study director: Prof. Dr. med. Jan de Laffolie
University Children's Hospital, Department of General Pediatrics and Neonatology, University
Giessen, Giessen, Hesse, Germany