



# Your **COMPARE** Handbook

Name: \_\_\_\_\_

# A Letter to You

Dear Patients and Families,

Thank you for agreeing to participate in the COMPARE Pediatric IBD Study!

Our names are Austin and Catalina. We are two **former pediatric IBD patients**. We know from experience what it's like to struggle to find medications that work for you. We are **partnering as Co-Investigators** with the COMPARE study team because we feel passionately about making sure research addresses the issues that are the most relevant toward patients – and does so in a way that is the least burdensome on families.

We know this is a difficult time in your and your child's IBD journey, so we are even more grateful that you are letting us join you on this journey to help learn how to help kids with IBD in the future. As you answer surveys or receive calls from our study team, know that **each answer you're providing brings us one step closer to being able to make better treatment decisions for pediatric patients**. Your data will undoubtedly help others like your child in the future. For us, participating in research has helped us channel the negative experiences of our disease into something positive – making lives better for those who come after us. We hope the COMPARE study offers you and your family this fulfillment as well.

Thank you for letting us join you on this journey! We look forward to making strides in the care of kids with IBD **together**.

Best,  
**Austin and Catalina**

Our **Parent and Patient Co-Investigators** have helped shape COMPARE to reflect real-life experiences and keep families at the heart of the study.

Look for their cartoon versions throughout this handbook as they're here to guide and cheer you on!



**Austin**



**Lisa**  
**("Anthony's Mom")**



**David**  
**("Zac's Dad")**



**Catalina**



# Welcome to the **COMPARE** Pediatric IBD Study!

We're so glad you're here. By joining COMPARE, you and your family are part of something bigger—a nationwide study that will help kids and teens with Crohn's disease and ulcerative colitis now and in the future.

Think of this handbook like your compass! It'll help you find your way through COMPARE!

Inside, you'll find:

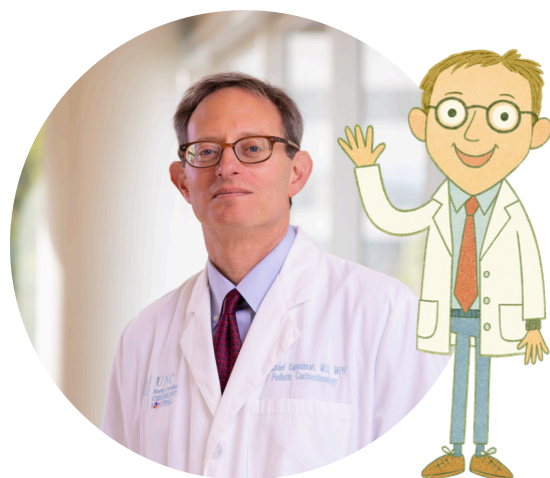
- What to expect during your child's time in COMPARE
- Study roadmap with a clear timeline and milestones
- Key contacts so you always know who to reach out to
- Compensation details for your time and effort
- COMPARE gifts from us to your family

Thank you for participating in the study. Your family's story will make a difference for kids everywhere living with IBD.

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## Meet Dr. Kappelman

**Dr. Michael Kappelman** is a pediatric gastroenterologist and researcher who has dedicated his career to helping kids and teens living with inflammatory bowel disease (IBD) feel their best. At UNC-Chapel Hill, he leads research that brings together families, doctors, and scientists to learn which treatments work best and how to make care easier and more consistent for everyone. Dr. Kappelman's goal is to understand what life with IBD is really like for young people and to use that knowledge to improve care for kids and families everywhere.



**Dr. Kappelman**

# COMPARE Overview

## What is the COMPARE Study?

COMPARE is a national research study for kids and teens with Crohn's disease or ulcerative colitis. When standard treatments stop working, families and doctors do their best with the info we have, but we need more. COMPARE is helping fill that gap by looking at how newer medicines work in real life. When you share your symptoms, it helps researchers see how treatments affect everyday life, so care keeps getting better for kids and teens in the future.

## Why Does COMPARE Matter?

- Helps doctors understand which medicines are most effective and safest.
- Gives families clearer information when making difficult treatment decisions.
- Builds a roadmap for better care in the future.

**Your experience could help the next family know what works best.**

## What's Involved?

- *Regular Care:* Your child's doctor chooses and manages their medicine—no changes for the study.
- *Surveys:* You will fill out short surveys every few months.
- *Optional Samples:* You may be asked to provide stool or blood samples, usually at times you'd already be visiting the clinic.

**The survey is quick and easy—just 10 minutes, and you're all set!**

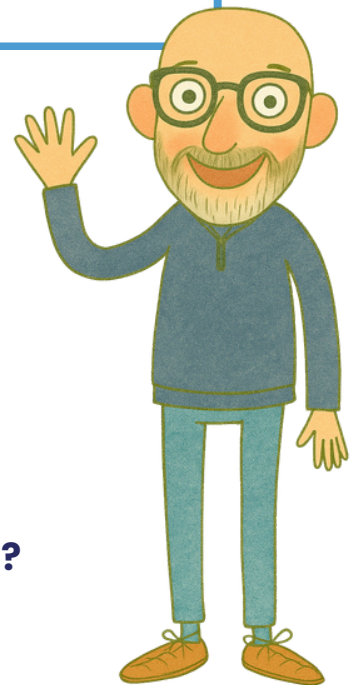
## What's Not Involved?

- No extra clinic visits.
- No extra medicines.
- No changes to your child's care plan.

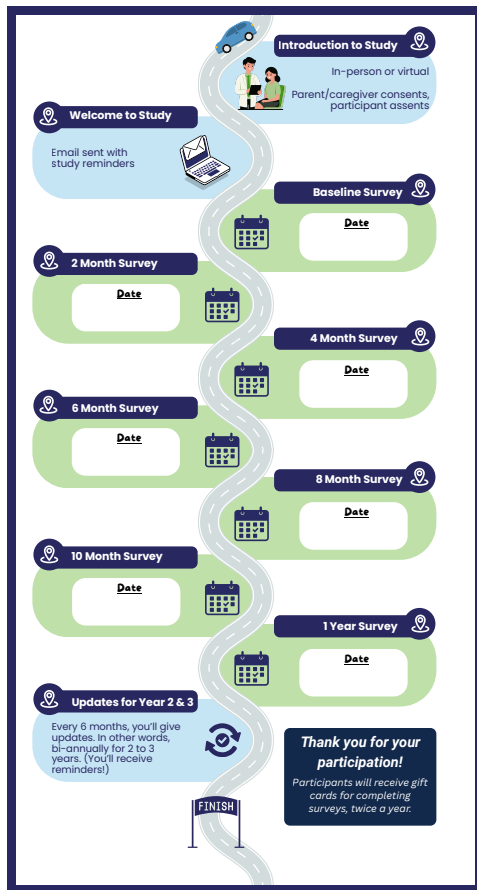
## How We'll Help

You're never on this journey alone.

- A study coordinator reviewed the consent form with you and will answer any questions you may have during the study.
- Our team will send gentle reminders (by text, email, or phone) so you'll always know when a survey is due.
- Our call center team is here to help with technical questions or participant payments.



# Your COMPARE Journey



## Your Journey Map

In your folder, you'll find a personal journey map. This map is designed to guide you through the study, and you can use it to record the dates when you complete each survey.

## Milestones

Your COMPARE journey has clear steps from start to finish.

- Starting Point (Baseline): First survey to get a snapshot of your child's care now.
- Check-Ins: Surveys at 2 months, 4 months, 6 months, 8 months, 10 months, and 1 year.
- Updates every 6 months after that (for up to 3 years).
- Thanks: You'll receive gift cards for your time completing surveys and sending stool samples.
- We'll occasionally share project updates and general info (no spam, promise!).

## Compensation

You'll receive Amazon e-gift cards as a thank-you for completing surveys and sending in the optional samples. Most participants will get their payments through the Duke Clinical Research Institute (DCRI) Call Center.

When you fill out the Participant Payment Form, be sure to include the email address where you want your gift cards sent.

- Baseline survey payments are sent within about 2–3 weeks after you finish your first survey.
- Follow-up survey payments are sent about every 6 months for any surveys completed during that time.
- You can earn up to \$220 for surveys and \$60 for two (optional) stool samples (\$30 each) — for a total of up to \$280 over the course of the study.

If you ever have questions about payments, please reach out to the DCRI Call Center at COMPARE-PRO@duke.edu. We're here to help!

**Your child's care stays the same. We just learn from their regular visits and treatments to help improve care for other kids.**



# Stool Sample Kit How-To

Let's be real, we know stool (or poop) samples aren't exactly anyone's favorite topic. It can feel a little bit awkward. Don't worry, this step is optional! If you choose to participate, we'll show you how to do it like a pro.

Your sample gives us valuable clues about how IBD treatments work and how we can make care better for other kids and teens.

Please also use the instructions given to you with the sample kit! Ready? Okay...let's get right to it!

*This might be weird,  
but it's super helpful!  
You got this!*



## Here's what to know before you start!

- Freeze your ice pack as soon as your kit arrives — it keeps your sample cool for shipping.
- Only collect your sample Monday–Wednesday, so it can be shipped before the weekend.
- Try to ship your sample the same day you collect it (or the very next day).
- Schedule pick up service with FedEx. It doesn't cost you any money. You can call them and set a pickup time, or drop your packed sample off at a FedEx location.
- Keep the packed sample in the fridge until you are ready to drop it off.

## Here's how it works!



1

Get ready. Open your kit and make sure you have everything. Ask an adult to help if you need it.

2

Collect your sample. Use the white bowl and holder to catch your poop — not the toilet water! Then scoop a small bit into the container and seal it up.

3

Pack it up. Put your container in the plastic biohazard bag with the white pad. Keep it in the fridge until it's time to ship.

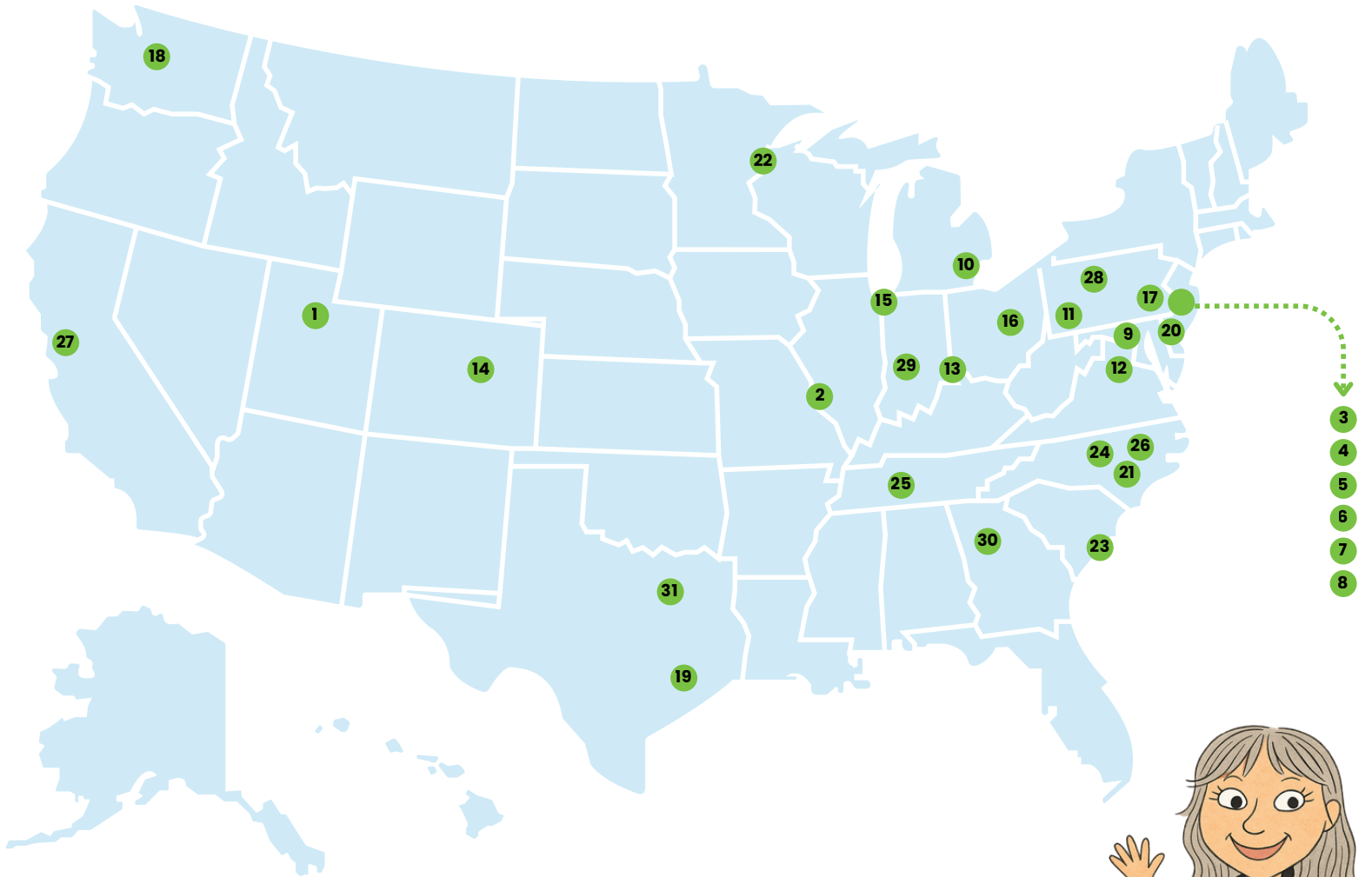
4

Ship it out. Add the frozen ice pack to the foam box, pack your sample, and send it through FedEx that day or the next.

**And that's it! You did something amazing!**

# COMPARE Sites

COMPARE isn't just happening at one hospital! Every dot on this map represents a COMPARE site. Together, they form a powerful network that makes this study possible. Whether you're in North Carolina, California, or somewhere in between, you're part of something much bigger, helping kids and families everywhere.



**See all those green dots? That's a whole lot of people working together with you!**

1. University of Utah
2. Washington University of St. Louis
3. Columbia University Irving Medical Center
4. Montefiore Einstein
5. Mount Sinai Health System
6. NYU – Langone Health
7. NYU – Lake Success
8. Weill Cornell Medicine
9. Johns Hopkins University
10. University of Michigan

11. University of Pittsburgh
12. Children's National Hospital
13. Cincinnati Children's Hospital
14. Colorado Children's Hospital
15. Lurie Children's Hospital
16. Nationwide Children's Hospital
17. Nemours Children's Health
18. Seattle Children's Research Institute
19. Texas Children's Hospital
20. The Children's Hospital of Philadelphia

21. Duke University
22. Mayo Clinic
23. Medical University of South Carolina
24. University of North Carolina
25. Vanderbilt University Medical Center
26. Wake Forest University School of Medicine
27. University of California, San Francisco
28. Penn State University (Penn State Health Children's Hospital)
29. Indiana University (Riley Hospital for Children)
30. Emory University (Children's Healthcare of Atlanta)
31. UTSW (Children's Medical Center, Dallas)



# COMPARE

## Contact Information



**Scan the QR Code to Save Our Contact Info!**

Toll-Free Number: **833-850-2848**

Email address: **COMPARE-PRO@duke.edu**

We are open 7 days in the week  
(daytime, evening, weekend).

If you're feeling bad and this is an  
emergency, please call 911 or contact your  
clinic!

### Important Things to Note

**You don't have to think about this study all the time. It's not something that you're not going to have keep tabs on! They'll send reminders about what needs to be done!**

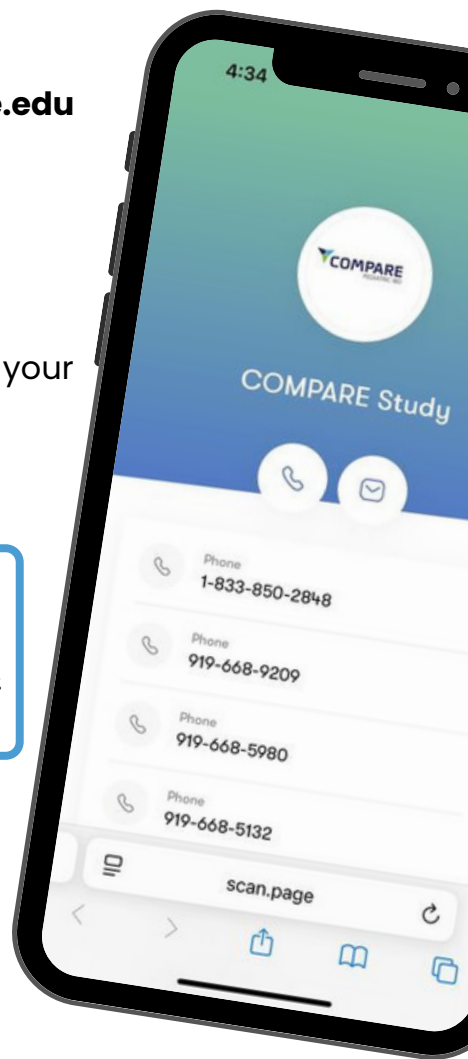
Every 2 months, you'll get an email with a link to complete your survey. If you miss one, the Call Center will send up to three reminder emails.

Messages will come from  
[duke\\_noreply@duke.edu](mailto:duke_noreply@duke.edu) or [no\\_reply\\_dcric@mc.duke.edu](mailto:no_reply_dcric@mc.duke.edu).

We are here to support you every step of the way in your COMPARE journey!

### Sharing General Updates

We'll let you know if we learn anything new that might change how you feel about your child staying in the study. Some basic study information will be listed on ClinicalTrials.gov, a public website, but it won't include your child's name or any personal details. We may share anonymous survey or health information with other researchers to help us all learn more about IBD in kids. Your child's name or contact information will never be shared. When the study is over, we'll let you know how to see the results.



# FAQs About COMPARE

## ? Who do I contact if I have any questions?

If you have questions about COMPARE, please call **833-850-2848**. If you have questions about your child's healthcare, call your clinic. If you're feeling bad, and this is an emergency, call 911 or contact your clinic!



## ? What if my information changes or I need to take a break?

If your email or phone number changes, let the Call Center or your site coordinator know so you don't miss any surveys or payments. If you ever need to take a break or stop participating, that's completely okay - just let us know! Your information will always stay private, and we'll never share your name or contact details with anyone outside the study.

## ? How do we get compensated?

You will receive compensation every 6 months. You will receive up to \$280 over the course of the study. Amazon e-gift cards will be sent to your preferred contact email address (either the child or parent/caregiver). If you have any questions about compensation, you may contact the Call Center.

## ? What if I forget a survey?

No worries! The Call Center will remind you and work with you! You may receive up to three reminder emails while your survey is open.

## ? How will my privacy be protected?

All data are de-identified before being shared. Names and personal details are removed, and each participant is assigned a study ID number. The study follows strict privacy and data security rules to keep your child's information safe.





# Thank you for being part of the **COMPARE** family!

Your participation in COMPARE is shaping the future of care for kids and teens with IBD. We are deeply grateful for your time, energy, and partnership.

We're here anytime you need us.

COMPARE will be in touch with you throughout the study and after to share what we have learned. A newsletter will be shared with you as well.

Use this space to write down the name and contact information for your study doctor or study coordinator. Keeping their details handy will make it easy to reach out if you have any questions or concerns during the study.



**[www.COMPAREIBD.org](http://www.COMPAREIBD.org)**

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## **Please note!**

If you're feeling bad and this is an emergency, please call 911 or contact your clinic!  
If you have questions about your healthcare, please contact your healthcare team.  
If you have technical questions about your COMPARE survey, call 833-850-2848.