

Research in Inflammatory Bowel Disease (IBD)

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Should I Participate
In a Research Study?



Overview

- Why to get involved in Research
- Current Research Opportunities

Rady Children's Hospital-San Diego

Why get involved in Research

Patients who get involved in research report benefits:

- 1) Access to newer and perhaps more effective treatments
- 2) Some people feel they are taking part in a positive experience and are taking an active part in their healthcare
- 3) Taking part could also benefit future generations by helping to find more effective treatments and cures



Principles of Research

- All research is reviewed by an Institutional Review Board
- Voluntary
- For youth to participate, assent obtained from youth and consent from parents
- Can withdraw participation at any time



Available Research Opportunities

- ImproveCareNow
- DEVELOP
- CAPE
- Vedolizumab Clinical Trials
- CAMEO
- REMODEL-CD
- CAPTURE

ImproveCareNow

A collaborative community of >100 centers where clinicians, researchers, parents and patients are empowered to learn and continuously improve to bring about more reliable, proactive IBD care for healthier children and youth.

**Rady Children's is a member of
ImproveCareNow**

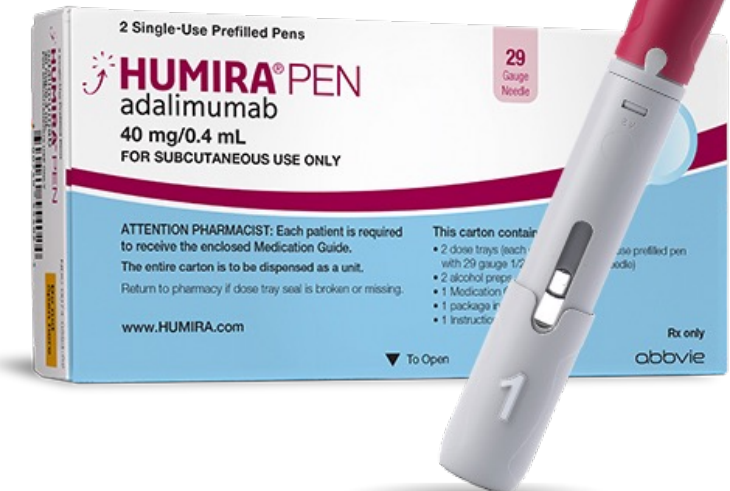


IMPROVE**CARENOW**[™]

DEVELOP & CAPE

Industry registry studies

- Enrolled youth on/off anti-Tumor Necrosis Factor agents
- Closed to enrollment but plans to follow-up current participants through adulthood.



Clinical Trials

BENEFITS:

Get medication free

Get testing free - Labs/Endoscopy

Also, compensation for time

- Vedolizumab (Ulcerative colitis and Crohn's disease) (Enrolling now)
- Mirikizumab (Ulcerative colitis and Crohn's disease) (Pending)
- Guselkumab (Crohn's disease) – (Pending)
- ABX464/obefazimod (ulcerative colitis) – (Pending)



GOALS

- A collaborative study being performed at 27 leading pediatric inflammatory bowel disease centers in the United States and Canada.
- The purpose of CAMEO is to help us understand why some children with Crohn's disease (CD) treated with a common form of therapy (anti-TNF biologics) heal their intestine and others do not.
- **Rady Children's Hospital : One of 27 sites nationwide**

BENEFITS:

Time compensation
MRE free

REMODEL-CD

BENEFITS:

Get medication
free x 1 y

GOALS

- Studying precision (patient specific) dosing of infliximab and biosimilars in newly diagnosed Crohn's Disease patients
 - Enrolling now
- **Rady Children's Hospital :**
One of 10 sites nationwide



Upcoming Research Opportunities

GOALS



BENEFITS:

Time compensation

- Create a cohort of 2,000 pediatric IBD patients and follow them throughout the course of their disease
- Participants in CAPTURE IBD will receive their usual care while sharing data about their health along with blood, stool, and tissue samples for use in the study.
- Researchers will then analyze data and aim to develop ways to identify patients as being likely responders or non-responders to specific types of biologic drugs.

Rady Children's Hospital : One of 11 sites nationwide



Summary

- Advancements in IBD management and treatment rely on research
- Rady Children's IBD Center participates in IBD research studies
- Many opportunities are available for participation in research
- Please consider joining the research participant community!